Profiling young carers' lives: An examination of individual, family, and social contexts

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Abstract

Young carers (YCs) who provide prolonged care for ill, disabled, or addicted family member(s) face a tremendous risk for negative developmental trajectories when remaining hidden (Charles, Stainton, & Marshall, 2009; Charles, 2011; Cass, 2007). Despite a growing recognition of YCs, understanding how providing care impacts a young person is not fully understood. The present study aimed to investigate circumstantial, family, and individual factors which may be associated with YCs' caregiving role. By comparing YCs to a normative sample, a comprehensive YC profile was formed. A secondary comparative analysis was conducted on 124 YCs (72 females and 52 males, M_{age} = 12) and a normative sample (n = 124) matched on YCs' age, gender, and number of siblings within the family. Unique attributes of the YC population were discussed, thereby creating a YC profile. Future research may be able to use this profile to promote identification and recognition of YCs.

Keywords: Young carers, caregiving, population differences, profile

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Cheers to the next chapter!

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Chapter One: Introduction

The Research Problem

In many countries around the world, there are hidden populations of children and youth with adult-like caregiving responsibilities, otherwise known as "young carers" (YCs). YCs are young people (under the age of 25) who provide prolonged care for ill, disabled, addicted family member(s) or in circumstances where parents may be absent or have language barriers in order to ensure family survival (Charles, Stainton, & Marshall, 2008; Charles, Stainton, & Marshall, 2009; Charles, 2011; Cass, 2007). Awareness regarding YCs' existence had originated in the UK and spread to other countries, including Canada, a decade ago. In the UK, the alarming findings and substantial prevalence rates with respect to YCs initiated immediate national practice, policy changes, and international awareness into exploring this topic.

As research began to examine YCs' lives, several noticeable problems unfolded. Many studies found that children with caregiving roles often completed more chores than other children their age as a result of having to provide care for ill or disabled family members (Becker, 2007; Nagl-Cupal, Daniel, Koller, & Mayer 2014; Warren, 2007). With their increased responsibilities, research illustrated that it was not uncommon for YCs to experience mental, emotional, psychological, social, educational, health-related and future-oriented disadvantages, with only a few identified benefits (Bolas, Wersch, & Flynn, 2007; Chalmers & Lucyk, 2012; Nagl-Cupal et al., 2014). Thus, it became clear; being a YC significantly affected children's developmental trajectories in a negative manner.

Correspondingly, the risk framing approach was quickly adapted (Heyman & Heyman, 2013). As the majority of research focused on exploring the types of YCs' responsibilities, YCs have begun to be viewed by others as children who were 'at risk' of losing their opportunities for normal childhoods due to their caregiving role (O'Dell, Crafter, de Abreu, & Cline, 2010; Heyman & Heyman, 2013). As a result of Western society's prominent views regarding childhood and family norms, young caregiving continued to gain a negative connotation (O'Dell et al., 2010; Heyman & Heyman, 2013). The prevailing societal views discouraged the young from having any caring responsibilities that exceeded the normal and expected levels of age-appropriate chores. Consequently, YCs received neither recognition nor validation for their caregiving roles (Gray & Robinson, 2009; Rose & Cohen, 2010; Thomas et al., 2003).

Nevertheless, being a YC is the reality for 12% - 28.2% of children and youth in Canada (Charles, Stainton, & Marshall, 2010; Remtulla, Charles, & Marshall, 2012; Stamatopoulos, 2015). The majority of them consider their role to be normal within their family context (Smyth, Blaxland, & Cass, 2011; Cass, 2007). Therefore, it is not surprising that many YCs either remain hidden due to non-identification or actively try to maintain secrecy because of a belief that others do not understand them (Bolas, Wersch, & Flynn, 2007; Moore & McArthur, 2007; Metzing-Blau & Schnepp, 2008; Ali, Ahlstrom, Krevers, & Skarater, 2012).

Unlike some identified YCs who may seek the support they require, others who do not identify themselves as YCs continue to provide care without the assistance they may need. Additionally, only a few seek support since the majority of YCs fear that identification may lead to worse outcomes such as family separation (Moore &

McArthur, 2007; Metzing-Blau & Schnepp, 2008; Smyth, Blaxland, & Cass, 2011). YCs' hidden nature may have serious implications that could exacerbate the negative outcomes for which they may already be at-risk. Increasingly problematic is the fact that many professionals do not possess adequate skills to properly identify YCs and may in fact ignore or be unaware of their existence or their unique needs (Gray & Robinson, 2009; Greenwood, Mackenzie, Habibi, Atkins, & Jones, 2010; Moore, 2005). Thus, the majority of YCs, and perhaps more than the estimated 12% - 28.2%, continue to exist unnoticed, thereby contributing to the lack of awareness in Canada and elsewhere. Despite the growing need for more awareness and recognition for YCs, a comprehensive YC profile is still missing from literature and practice.

Literature that examined factors that may explain why one becomes a YC mainly focused on the familial conditions such as SES, family composition, and support availability (Ireland & Pakenham, 2010; Fives, Kennan, Canavan, & Brady, 2013; Metzing- Blau & Schnepp, 2008). There were limited attempts to examine individual-based factors. For instance, age and gender have been investigated, but often used for demographic purposes or for extending information on YCs' characteristics. In fact, there is no literature on YCs' personality traits and/or birth order that could potentially explain caregiving within the family.

In practice, since a profile of YCs is still missing in the literature it makes it harder to make successful identifications (Thomas et al, 2003). Many researchers suggested that identification of YCs may be completed by asking questions, even if they seem sensitive to some families (Charles, 2011; Tuffrey, 2012). However, it could take years before professionals and other agency workers feel comfortable to ask questions

without feeling as though they are intruding on private family matters. It is not surprising that most social service professionals (e.g., social workers, doctors, nurses, and teachers) who should be able to identify YCs simply look past them (Gray & Robinson, 2009; Underdown, 2002). Without a comprehensive profile, there are only limited contexts such as schools, hospitals, and other agencies that are interested in identifying and supporting the YC population.

Statement of the Problem

YCs face a tremendous risk for negative developmental trajectories when remaining hidden. While the predominant negative view about what YCs do in the family may discourage recognition and validation of their role, it should not affect identification and provision of support. Unfortunately, the lack of awareness and knowledge of YCs makes it possible and prevalent for professionals to ignore this population of children and youth. But how should support be provided if no one yet knows or understands what a YC looks like? Thus, it is clear that the welfare of YCs is dependent upon an adequate profile that is yet to be developed.

Purpose of the Study

The present study sought to build upon existing research and extend the knowledge regarding YCs in Canada. The lack and limitation of previous literature made a perfect platform for a study that explored 'who is a YC?' as it examined the children's caregiving role in the individual, social, and family contexts. By investigating many factors at once and comparing the YCs to a normative population, this study aimed to close the research gap by developing a new, comprehensive YC profile.

Specifically, this study explored family, individual, and various psychosocial variables to assess what YCs look like. In order to describe YCs' role within the family, factors such as family composition, proximity/availability of others, SES, amount of support required, who needs care and why, and usage of other formal support were analysed. The present study aimed to replicate previous findings but in a Canadian context, where research is currently lacking.

Simultaneously, by investigating individual factors (e.g., age and gender), this study aimed to extend existing literature by offering to examine two additional factors that have never been explored - birth order and temperament. Additionally, by also evaluating psychosocial factors, this study intended to use comparative analyses to establish how YCs differed from non-caregiving youth, thereby creating a YC profile.

Rationale and the Importance of This Study

There is a tremendous need for an adequate and systematic way to identify what a YC within the family context looks like. Without a comprehensive YC profile, professionals will continue to lack awareness and/or skills to identify or develop programs to assist them, and YCs and their families will remain hidden from the general population. Knowing more about who assumes the caregiving role within the family, and how they differ from others in the general population will provide better assessment, support services, and recognition of all children who may have extensive responsibilities at home.

The importance of creating a profile.

Since, for many children, taking on caring responsibilities may be seen as a normal familial duty, a profile can assist them in identifying themselves as YCs and

seeking recognition for their role as carers (Cass, 2007). Additionally, studies showed that there were benefits to identifying oneself as a YC. Smyth, Blaxland, and Cass (2011) found that identification yielded all kinds of positive outcomes for YCs; once recognized, YCs felt validated and got acknowledgement for their role as a carer. They also noted it was easier to explain their circumstances to others, to seek the necessary support, and they felt empowered to know they were not alone (Smyth, Blaxland, & Cass, 2011).

While identifying as YCs is beneficial, it is only a minor part of the solution. Agencies and other services that work with families must be willing to identify YCs and be skilled at knowing how to support them. Instead of relying on asking questions, having a YC profile can ease and enhance the identification process. Understanding the typical profile of a YC may provide an advantage to some professionals as they try to identify children who may be at risk for adopting caregiving roles and help mitigate or provide support to these families. Thus, not only can a profile contribute to improved assessment and identification of YCs, but it can also promote better interventions. Viola, Arno, Siskowski, Cohen, and Gusmano (2012) suggested that it was necessary for health care professionals to include identification processes in their everyday practices which means that they should know, recognize, and support YCs.

Theoretically, this study promoted a greater understanding of the factors that were associated with caregiving behaviours. Specifically, this study described YCs' circumstances within different contexts and demonstrated whether the YC phenomenon was any different from a non-caregiving population. Practically, by building a profile, this study aimed to increase knowledge in the professional field and to improve the identification process which could lead to greater societal recognition of the YC

population and to improved outcomes for YCs themselves. Finally, this study hoped that the results would influence future policy by providing funding for interventions that would enhance support plans by targeting specific factors early on in children's lives prior to them becoming YCs.

Research Questions

In order to build a comprehensive profile of a YC, this study aimed to answer the following questions:

1. Who is a young carer within the family context?
2. Are young carers different from non-young carers?
3. What does a young carer profile look like?

The first step necessitated a description of who is a YC within the family. The second step illuminated population differences, specifically looking at YCs' characteristics. The final stage required developing a preliminary YC profile to promote awareness and knowledge of YCs in Canada and elsewhere. Since there was a limited amount of research with regards to this topic and the present study was mainly exploratory, no hypotheses were made.

Theoretical Framework

This study examined the caregiving behaviour as it differed across adult and child populations. Conceptualizations of childhood, family systems approach, and gender role theory were adopted to better understand the YC phenomenon and the potential factors that explained YCs' unique characteristics.

Chapter Two: Review of Related Literature

Discussions regarding "young carers" require understanding of two distinct terms: 'the young' and 'the carer'. In Canada and in similar societies, aspects of the caring behaviour and children's role in caregiving are influenced by certain cultures, age groups, and genders and thus may be viewed differently. This literature review provides an account of the caring behaviour that is expected of informal adult caregivers and compares it to the role that children may play in caregiving in order to better understand how these normalized behaviours contrast with what constitutes a "young carer" and contributes to their hidden nature. With the primary goal of developing a YC profile, this literature review ends by examining how circumstantial, family-oriented factors, certain individual, person-focused variables, and psychosocial features can contribute to or may explain the caregiving role in a family context. Lastly, a small number of studies that examined population differences is noted.

The Caring Behaviour

Caring within the family.

Informal caregiving has been an increasing trend in many countries around the world, including Canada. Providing and/or receiving care is normal and even expected in some families. When the need arises, family members support one another through various life circumstances. Brown and Brown (2014) define caregiving in broader terms to include informal caregiving which is a type of a prosocial, helping behaviour provided to those in need. In many occasions, family relatives or spouses feel obligated to take care of their ageing members and assist others who may have acquired health problems (Parveen, Morrison, & Robinson, 2011; Williams, Morrison, & Robinson, 2014). Often,

their caring role is considered a familial duty and the perceived lack of choice is explained by their love for one another and the drive to support their family members no matter the circumstances (Parveen et al., 2011; Williams et al., 2014; Sawatzky & Fowler-Kerry, 2003).

Caring based on gender.

It is considered a commonly held belief that females provide more care than males. Indeed, previous literature notes that adult females were more likely to provide care than adult males (Belansky & Boggiano, 1994; Aronson, 1992; Wolf, Freeman, & Soldo, 1997). Daughters were found to provide three times more care than sons and be named the 'primary caregiver' within the family (Coward & Dwyer, 1990). In gender-related studies with siblings, adult female siblings were more likely than adult male siblings to become the coordinator for caring activities (Hequembourg & Brallier, 2005). In more recent studies, males contributed but often provided care in lesser quantities (Karniol, Grosz & Schorr, 2003; Hequembourg & Brallier, 2005). Thus, caring is often provided by adult female caregivers.

A great deal of research established that caring tasks are gendered as well. Studies found that males provided care by taking on tasks that were different from females'. For instance, while females were more likely to assist with emotional and nurturing support as well as household tasks (i.e., cooking and cleaning), males contributed by accomplishing non-routine tasks, maintenance tasks (i.e., lawn work and repairs), as well as physical activities that required lifting and assisting with mobility (Belansky & Boggiano, 1994; Hequembourg & Brallier, 2005; Dwyer & Seccombe, 1991; Aronson, 1992). In some instances, adult males' involvement crossed gender stereotyped roles. A

study by Hequembourg and Brallier (2005) found that adult male siblings who were identified as "co-providers" relied on their sisters to coordinate their care, but often provided emotional care and got involved in other tasks that were considered more "female" oriented (p. 62). The study also found that the inequality in gendered caregiving could potentially stem from parents' expectations of what each gender should do when providing care (Hequembourg & Brallier, 2005).

The caregiving experience.

In a Canadian study by Williams, Wang, and Kitchen (2014), caregiving was associated with negative outcomes, regardless of who the caregivers provided care for. A common finding was that caregivers compromised their health, restricted their social and financial support, and hindered their careers while caring for their loved ones (Williams et al., 2014; Sawatzky & Fowler-Kerry, 2003). Depending on the caregiving duties, hours spent caring, and the use of additional support, Groenou, de Boer and Iedema (2013) found that all caregivers felt some degree of burden when caring for others, but they all had the possibility to reduce their stress by asking for help from other sources.

Although most research is focused on the heightened burden from caregiving, Brown and Brown (2014) argue that caring is part of human nature and if the costs would have outweighed the benefits, this behaviour would have stopped long ago. Presently, more studies find that there are a few benefits to caregiving. There is evidence from previous literature that claims that caring may in fact contribute to higher well-being when the caregivers are supported by others and to greater levels of happiness when the caregivers spend between 1-5 hours on caring per week (Hoefman, Exel, & Brouwer, 2013; Campen, de Boer & Iedema, 2013).

Overall, the caring behaviour of an informal carer is expected due to their sense of a familial duty to assist their family members. Informal carers are responsible adults, usually females, who provide care that can either hinder or benefit their lives. Despite the outcome, they may feel obligated to help. All in all, there is a great deal of support and recognition for their caregiving roles.

Children's Role in Caring

Today, children may not be required to take care of their family members until they become older, and even then it is a matter of circumstance. However, a majority of children and youth are expected to contribute to the family by completing chores such as babysitting, making one's bed, preparing meals, doing dishes, doing laundry, helping to clean rooms, and vacuuming the house (Klein, Graesch, & Izquierdo, 2009).

Children and youth are being motivated and encouraged from an early age to complete various age appropriate chores in order to build their character and to become more responsible individuals (White & Brinkerhoff, 1981). It has been found that females and older children do the majority of the household tasks (Klein et al., 2009; White & Brinkerhoff, 1981). Moreover, there has been a gender split with respect to the type of chores. For instance, while girls would be responsible for the caregiving and cleaning tasks, boys would have more outdoor tasks (Klein et al., 2009; Goodnow, Bowes, Warton, Dawes, & Taylor, 1991).

Children's role in caring and completing chores is a normative, family-oriented, and expected stage in the majority of families (White & Brinkerhoff, 1981; Klein et al., 2009). However, the number of chores assigned may fluctuate differently within each family. Families may encourage different levels of assistance based on their individual

needs and circumstances. Thus, even though there is no baseline for what constitutes a normal number of chores in a regular family, an effective way to understand caregiving roles within a family requires viewing it on a continuum of care (Aldridge & Becker, 1999; Becker, 2007).

The caregiving continuum.

Normal caring occurs when the relationship between the care provider and care recipient is reciprocal and when caring is considered to be a family oriented task (Aldridge & Becker, 1999; Eley, 2004). Children who provide 'normal' care can be placed along the 'light' end of the continuum, where they would have age appropriate responsibilities (Becker, 2007, see Figure 1).

It is possible that, depending on the illness and care recipient's needs, the time spent on caring exceeds normal expectations of what a child should do (Smyth, Cass, & Hill, 2011). These children would assume 'heavier' caregiving responsibilities and can be placed at the 'heavy' end of the continuum (Becker, 2007; see Figure 1). In this stage, children are often considered young carers and may be in need of assistance (Aldridge & Becker, 1999).

When caring continues in an environment which lacks support, children often become 'at risk'; neither their needs are being met nor support is being offered (Aldridge & Becker, 1999). If this continues, the reciprocity of care diminishes and parentification is likely to occur. At this last stage of caring, the roles of children and parents become completely reversed and more adverse outcomes are likely to occur (Aldridge & Becker, 1999). Studies have found that children in this condition are more likely to become self-defeating, narcissistic, and shame-prone in their adulthood (Jones & Wells, 1996; Wells

& Jones, 2000). Thus, it is evident that caring progresses through certain stages; it may begin with babysitting or preparing meals and end with children becoming the primary caregivers, in which case it could lead to more severe outcomes. Although the caring continuum is a great way to comprehend the role that children play in caregiving, the present study focuses solely on young carers who take on the caregiving roles earlier than expected of them and before they are even ready for them (i.e., beyond cultural expectations or at a young age) (Miller, 2012; Charles, 2011).

<table>
<tr><td>'Light end' (low levels of caregiving and responsibility)</td><td colspan="2">→ → → → → → 'Heavy end'</td><td>'Very heavy end' (high levels of caregiving and responsibility)</td></tr>
<tr><td>'Routine' levels and types of caregiving including some help with Instrumental Activities of Daily Living</td><td colspan="2" rowspan="3">→ → →
Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration</td><td>'Substantial, regular and significant' caregiving including considerable help with Instrumental Activities of Daily Living</td></tr>
<tr><td>Household tasks and caregiving tasks can be considered age and culturally appropriate for the child's age</td><td>Household tasks and caregiving tasks can be considered age and culturally inappropriate for the child's age</td></tr>
<tr><td>Most children</td><td>Few children</td></tr>
<tr><td></td><td>Young carers providing 0–19 hours of care per week</td><td>Young carers providing 20–49 hours of care per week</td><td>Young carers providing 50+ hours of care per week</td></tr>
<tr><td></td><td colspan="3">Many 'hidden' young carers (unknown to service providers)</td></tr>
</table>

Figure 1. Becker's (2007) continuum of care

Caregiving by Young Carers

Informal caregiving is often provided by adult caregivers, but lately, awareness has been drawn towards children and youth who, under certain familial circumstances, complete more than simple chores; they take care of their family members. Previous research has classified them as "young carers" (YCs). YCs (under the age of 25) provide prolonged care for ill, disabled, addicted family member(s) or in circumstances where parents may be absent or have language barriers in order to ensure family survival (Charles et al., 2008; Charles et al., 2009; Charles, 2011; Cass, 2007). In all cases, their caring responsibilities exceed what is deemed to be normal or expected from their ethnic backgrounds or age (Charles, 2011; Miller, 2012).

However, it is important to note that not all children who grow up with family members who require assistance become YCs (Aldridge & Becker, 1999; Eley, 2004). Children who end up adopting caregiving roles may have different circumstances, experiences, and impacts. While some may become resilient, others may become helpless and in need of immediate support.

Caregiving tasks and responsibilities.

The majority of children are expected to complete the chores that are assigned to them by their parents. YCs have their own set of chores, but on top of it, they also have other greater responsibilities that their non-caregiving peers may not have (Nagl-Cupal et al., 2014; Warren, 2007). In most cases, if children do not complete all the chores, it is possible that somebody else in the family would finish it. However, in most YCs' families, non-completion of chores means that they would have to do them another day, as there is absolutely no one else who could help them.

Since YCs are responsible for a great deal of tasks, previous studies have clustered their responsibilities into the following categories: domestic and general tasks (e.g., cooking, cleaning, vacuuming, doing dishes, shopping for food, filling out paperwork or doing the finances), child care tasks (e.g., supervising or taking care of siblings, babysitting), intimate or personal care (e.g., changing, toileting, dressing, lifting, feeding), emotional and mental support (e.g., staying close by when recipients do not feel good, monitoring their condition), and medicine or nursing care (e.g., administrating medicine, going to a doctor, making appointments) (Fives et al., 2013; Warren, 2007; McDonald, Cumming, & Dew, 2009; Sahoo & Suar, 2010). Clearly, YCs have a heavier work load than other peers their age. They also spend a greater amount of time completing these tasks. YCs spend on average anywhere from 7-27 hours per week on caring, which is significantly more than the two hours per week their peers are responsible for as they complete their chores (Banks et al, 2001; Nagl-Cupal et al., 2014; Moore, McArthur, & Morrow, 2009; Warren, 2007).

The choice to care.

Similar to informal adult caregivers, YCs sometimes report that they had no choice but to take care of their family members (Bolas, Wersch, & Flynn, 2007). As a result, a few YCs claimed to have trouble explaining why they cared for their family members as they perceived it similarly to the adult caregivers'- as a familial responsibility (Bolas, Wersch, & Flynn, 2007; Banks et al., 2002; Cluver, Operario, Lane, & Kganakga, 2012). Some even viewed caring as a stressful obligation (McDonald, Cumming, & Dew, 2009; Earley, Cushway, & Cassidy, 2007).

Depending on the perceived level of choice, YCs report positive or negative outcomes from caring. For instance, if YCs perceived that they had a great deal of choice, they scored higher on life satisfaction and positive affect, lower on distress, and had more adaptive coping strategies (Pakenham, Chiu, Bursnall, & Cannon, 2007). Conversely, perceived lack of choice was associated with feeling confused, angry, overwhelmed, and frustrated (Bolas, Wersch, & Flynn, 2007). It was also correlated with poorer health outcomes (Ireland & Pakenham, 2010). In most cases, Smyth, Cass, and Hill (2011) found that "caring was not a conscious choice: it was simply something to be done, because they were 'born into it' or there was no one else to do it" (p. 512). Thus, while a few children may have a mindful choice regarding caring for their family member(s), others are simply brought up in families where regardless of one's choice, caring is required, regular, and expected assistance.

The caring experience: Positive and negative associations.

The most common positive gain from caregiving is maturity and responsibility (Banks et al., 2002; Fives et al., 2013; Nagl-Cupal et al., 2014; McDonald, Cumming, & Dew, 2009). These outcomes made most YCs feel good, useful, and capable which often promoted feelings of pride and security (Bolas, Wersch, & Flynn, 2007; Ali et al., 2012; Chalmers & Lucyk, 2012). Some studies also found that the relationships between YCs and the care recipients improved by getting to be closer as a result of the caregiving role (Stallard, Norman, Dickens, Salter, & Cribb, 2004; Chalmers & Lucyk, 2012; Doutre, Green & Knight-Elliott, 2013; Charles, Marshall, & Stainton, 2010). In other studies, the caregiving role had a positive influence on YCs' personality. A number of YCs claimed

that they became more caring, altruistic, enduring, and sympathetic (Charles, Marshall, & Stainton, 2010; Sahoo & Suar, 2010).

Not all YCs experience positive outcomes. Most literature shows that caregiving has a predominantly negative influence on YCs' lives. In many studies, YCs report that they have no time for friendships or social events (Ali et al., 2012; Chalmers & Lucyk, 2012; Warren, 2007). They either experience social discomfort or, since they are different from most peers, some get bullied and called names (Bolas, Wersch, & Flynn, 2007; Richardson, Jinks, & Roberts, 2009; Earley, Cushway, & Cassidy, 2007; Warren, 2007; Cree 2003). YCs who are found to be embarrassed by their role as a carer try to restrict their social lives further by not inviting their friends over (Polkki, Ervast, & Huupponen, 2004; Stallard et al., 2004).

Emotionally, studies found that YCs may exhibit higher levels of anxiety, worry, stress, and a greater number of emotional outbursts (Polkki, Ervast, & Huupponen, 2004; Chalmers & Lucyk, 2012; Ali et al., 2012; Earley, Cushway, & Cassidy, 2007; Hamilton & Adamson, 2013). They may also show more anger and guilt, as well as be more overwhelmed and frustrated (Bolas, Wersch, & Flynn, 2007; Earley, Cushway, & Cassidy, 2007; Doutre et al., 2013).

Research also found psychological distress where YCs may experience higher levels of depression, lower levels of life satisfaction, self-esteem and well-being (Banks et al., 2002, Banks et al., 2001; Chalmers & Lucyk, 2012; Collins & Bayless, 2013). Some YCs may report having poorer health and lower scores on happiness overall (Lloyd, 2013; Hamilton & Adamson, 2013). As a result, it is not surprising why some YCs experience more behavioural problems such as self-harm and difficulty sleeping, as

well as lower concentration which could then relate to one's educational trajectories (Cluver et al., 2012; Cree, 2003; Collins, & Bayless, 2013; Nagl-Cupal et al., 2014; Warren, 2007; Thomas et al., 2003). Many YCs may receive poorer marks, miss more days of school, and even drop out in order to provide for their families, all of which may have associations with poorer future financial standing and career choices (Fives et al., 2013; Moore, McArthur, & Morrow, 2009; Warren, 2007; Lloyd, 2013; Hill, Thomson, & Cass, 2011; Hamilton & Adamson, 2013). Overall, the research by Sahoo and Suar (2009) illustrates how the condition within the family impacts YCs' physical, mental, and social states both positively and negatively. The consequences of caregiving can be very serious (see Figure 2).

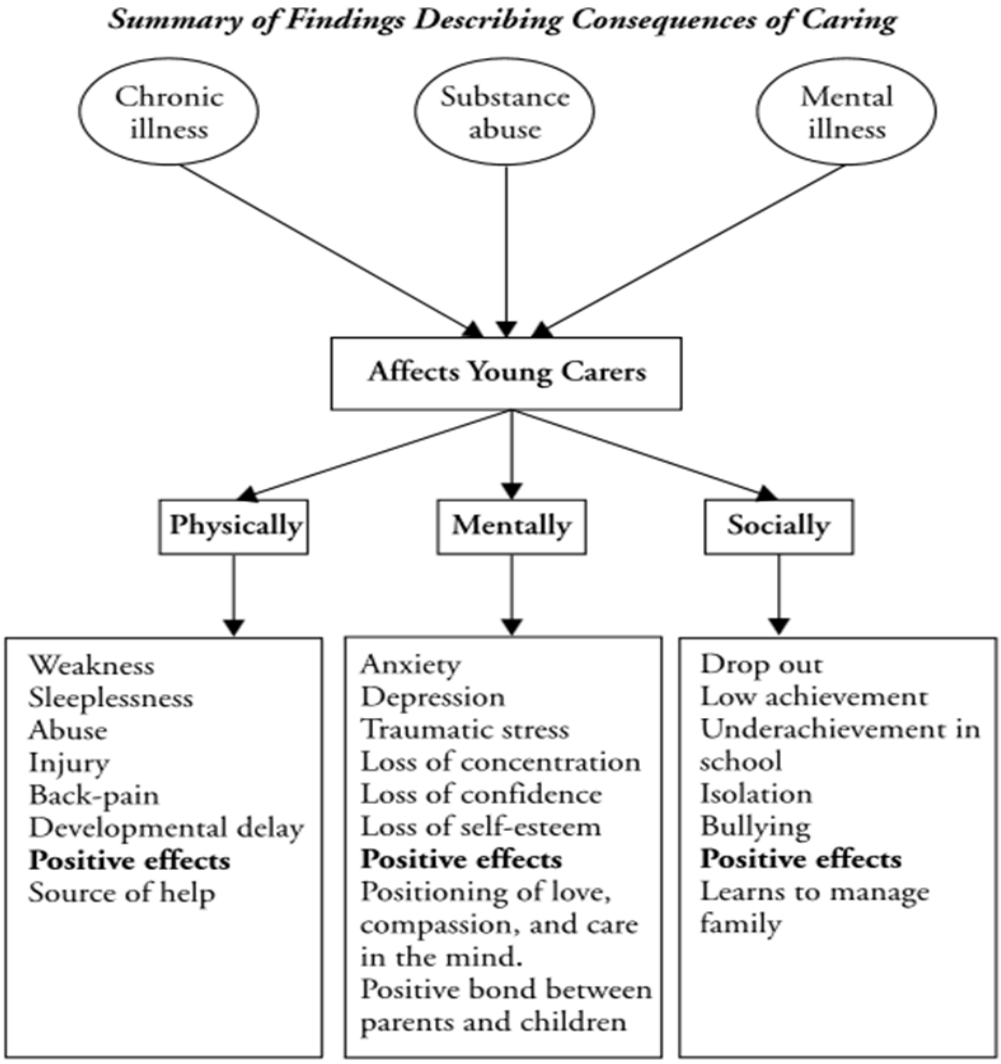


Figure 2. Sahoo and Suar's (2009) caregiving consequences

To summarize, despite one's choice for caring and his/her engagement with the caring role, YCs are perceived differently than adult carers. While informal caregiving by adults is normalized, expected, and even encouraged, caregiving by children is not. As demonstrated in research, the impact from caregiving is largely negative. As a result, others tend to see these children as being 'at risk'. This can contribute to increased secrecy among the carers, which may in turn have a negative effect on the recognition and awareness of YCs.

Young Carers' Hidden Nature

Reasons for secrecy.

First, YCs' hidden nature may be attributed to societal views and risk framing of YCs. Contrary to adult caregiving, child caregiving is criticized and often deemed as inappropriate. The role of providing care is socially constructed as an activity that is executed by parents or adults, not by children (O'Dell et al., 2010). Thus, while it is viewed as 'normal' for parents and other adults to take care of their children, it is deemed as 'unnatural' for it to be the other way around when they are young (O'Dell et al., 2010).

When children and youth take on a significant caring role, they are being compared to other 'normal' children, which then makes some people believe that they either lose or miss out on their childhoods (O'Dell et al., 2010). Heyman and Heyman (2013) found that risk framing is popular among professionals who view YCs as children who miss out on important life opportunities. This predominant view comes into conflict with certain families whose survival depends upon YCs' existence. Cass (2007) found that YCs and their families fear unwanted intervention and involvement of child protection services. As a result, families actively try to remain hidden since getting noticed by others increases the chances for investigation and even potential familial separation (Moore & McArthur, 2007; Metzing-Blau & Schnepp, 2008). Some parents may not want the children to get involved and try to protect and shelter them from others who may potentially upset them (Stallard et al., 2004)

Second, the use of the term 'young carer' provides a label for the purposes of identification. However, a comprehensive definition is lacking and thus it is still unclear what factors constitute a YC (Eley, 2004; Doutre et al., 2013). There is even a lack of

consensus with respect to the term and the age group used within the definitions (Doutre et al., 2013). Instead of using the term YCs, some research from other countries may call them "young informal carer", "sole carer", "supportive carer", or "primary carer" (Pakenham et al., 2007; Ali et al., 2012; Collins & Bayless, 2013). Additionally, even though most research claims YCs to be 18 years old and younger, some consider the age of 25 to be a more inclusive age category (Charles, 2011; Cree, 2003; Hamilton & Adamson, 2013). The absence of a clear definition can make identification very confusing.

Unclear definitions may have a great effect on prevalence rates. Different studies have found various prevalence rates, but it is still unclear how many YCs truly exist because the definitions may either be too inclusive or constrictive (Pakenham et al., 2007). Nagl-Cupal et al. (2014) found a 4.5% prevalence rate for YCs aged 10-14 in Austria. McDonald, Cumming, and Dew (2009) claimed that there are 4.2% (aged 15-18) and 4.7% (aged 19-24) of YCs in New Zealand. Banks, et al. (2002) found that in Scotland, 6.1% children aged 11-17 identify as a YC. Becker (2004) reported that there were approximately 7% of YCs (up to age 24) in the UK and Hunt, Levine, and Naiditch (2005) found around 3% in the USA (as cited in Smyth, Cass, & Hill, 2011). In Canada, 12% of youth (in high school, up to age 18) are considered YCs (Charles, Stainton, & Marshall, 2010; Remtulla, Charles, & Marshall, 2012). However, a more recent Canadian study found a higher prevalence rate, 28.2%, in youth aged 15-24 (Stamatopoulos, 2015).

Nevertheless, these prevalence rates may be underestimated due to the fact that it is extremely difficult to study, and even tougher to reach the entire YC population because young people may not identify themselves as YCs (Smyth, Cass, & Hill, 2011;

Moore & McArthur, 2007). Additionally, the lack of consensus on the definition means that research studies may use different inclusion criteria to obtain those percentages thereby creating unclear interpretations and the potential for overestimation. For instance, the age criterion of 25 is more inclusive than an age limit of 18. Moreover, in many research studies, the questions that help identify YCs are inconsistent. Nagl-Cupal et al. (2014), similarly to Remtulla et al. (2012), consider children YCs if they have a family member with an illness or disability and they help them in some way. Banks et al. (2002) extends the criteria by including other problems that yield caregiving such as drugs and alcohol, while Stamatopoulos (2015) highlights the unpaid work aspect of this type of caregiving. Thus, the insufficient definition, inherited inconsistencies, and absence of clear prevalence rates could very easily contribute to the lack of understanding, awareness, and identification of these children.

Third, using the label 'young carers' does not mean that everyone who provides care recognizes themselves this way. Research found that some YCs do not see this label as part of their identity (Rose & Cohen, 2010; Moore & McArthur, 2007; Charles, 2011). Smyth, Blaxland, and Cass (2011) claimed that their sample of YCs view themselves as family members helping around the house; they may perceive 'caring' as a normal part of life, where they simply do it because it is expected of them (Cass, 2007). By not knowing who they are, they continue to lead their lives as YCs, but remain hidden from others' recognition. Thus, the inadequate use of labeling can further silence and marginalize them (Watson, 1999).

Fourth, since feeling different may be an unpleasant experience for some youth, it is possible that those children who are YCs may not want to be associated with this label

(Metzing-Blau & Schnepp, 2008). A number of studies found that some YCs felt ashamed of their caring roles and, since they believed that there was a stigma associated with illness and disability, they actively tried to hide the fact that they were YCs (Bolas, Wersch, & Flynn, 2007; Moore & McArthur, 2007; Richardson, Jinks, & Roberts, 2009). Additionally, some YCs feared being bullied and/or harassed as a result of their caregiving role (Moore & McArthur, 2007). In certain conditions, it may be easier to hide the caregiving role than to deal with some of the consequences.

Implications of secrecy.

Since the predominant view about YCs is negative and risk-framed, YCs may not receive the proper support or recognition. It has been found that several services may believe that YCs are too young to be able to provide care (Gray & Robinson, 2009). Consequently, it is unfortunately prevalent for professionals and other service delivery workers to ignore or ostracize YCs for what they do (Gray & Robinson, 2009). Another study that explored general practitioners in the UK found that the majority felt they did not receive adequate training to support YCs and less than half were able to properly identify them (Greenwood et al., 2010). There are even reports suggesting that some agencies lack the knowledge about how to make referrals to appropriate services (Moore, 2005). Thus, this clearly impacts the support YCs should be able to receive.

The predominant view of YCs may have a negative effect on their lives. A meta-analysis by Rose and Cohen (2010) found that "it was difficult for young carers to establish a positive self-identity and execute their caring duties, as they were not seen as consistent with socially accepted constructions of childhood" (p. 481). Some YCs reported that they often got excluded from important discussions because professionals

perceived them to be too young to understand what they were dealing with (Underdown, 2002). Bolas, Wersch, and Flynn (2007) found that YCs often kept their caring role a secret, fearing judgment or rejection from others. Maintaining secrecy can result in feelings of abandonment, worry, isolation, sadness and hopelessness, as well as lower life satisfaction, poorer health, and employment and career restrictions (Chalmers, & Lyuck, 2012; Bolas et al., 2007; Collins & Bayless, 2013; Lloyd, 2013; Smyth, Blaxland, & Cass, 2011). Thus, by remaining hidden, not only could it eliminate the chance for seeking support, but it could also increase the likelihood of negative outcomes associated with YCs' lives.

Finally, YCs' hidden nature can also have implications for future research; as this population is becoming tougher to reach, it becomes harder to obtain representative samples. Kennan, Fives, and Canavan (2012) ran into various hardships in their study with YCs in Ireland. Since the YC population was extremely hidden and no services were available at that time, they relied on self-referrals as well as referrals from gatekeepers. Unfortunately, no self-referrals were made and they found that in most cases, it was hard to explain to the gatekeepers what they were trying to do (Kennan, Fives, & Canavan, 2012). Additionally, in a study by Stallard et al. (2004), YCs' parents either feared the consequences from participating in their study or were in denial about how their disability can impact their children.

To conclude, the lack of knowledge, awareness, support, and recognition of YCs may increase ignorance within communities, which can further hinder YCs' development and contribute to their isolation and hidden nature. In order to make YCs visible, the identification process and the provision of support must be enhanced.

Factors Influencing the Caregiving Role

Circumstantial, family-oriented factors for caregiving.

In order to become more cognizant of what could potentially explain the YC phenomenon, some studies focused on examining YCs' circumstances and other family-oriented conditions.

Family composition. Ireland and Pakenham (2010) found that YCs often come from single parent households and thus may have more caring responsibilities than others who come from dual parent families in which caring duties may be divided among and shared between others. Similarly, Banks et al. (2001) found that above average caregiving roles are more prevalent among single parent households.

SES. Another common characteristic of the family is that YCs often live in households with lower SES (Fives et al., 2013). The inability to afford other services may make one more susceptible to assuming the caregiving role themselves (McDonald, Cumming, & Dew, 2009).

Why need care. The circumstances that make one vulnerable to becoming a YC include having someone in the family with a disability, mental illness, or behavioural or learning problems that require daily living assistance (Cree, 2003). Other circumstances may include language barrier and parental absence (Charles, Stainton, & Marshall, 2009).

Who requires care. Studies also show that most children reported to care for their mothers first, then for their siblings (Shifren & Kachorek, 2003; Ireland & Pakenham, 2010). Other studies may contain different findings since it is mostly based on familial circumstances of who requires the most care within each sample.

Amount of care required. With regards to factors that influence the amount of caregiving, some studies found the condition of the illness to be a potential predictor. Ireland and Pakenham (2010) found that the onset of the disease may impact the amount of caregiving. For instance, children are required to care more often if the onset of disease is sudden. Another important influencing factor is the severity of the illness; severe illness may elicit more caregiving (Metzing- Blau & Schnepp, 2008). Conversely, better disease prognosis yields less caregiving (Ireland & Pakenham, 2010).

Availability and proximity of other support. Other circumstantial factors that may impact ones' acquisition of the caregiving role include the availability and proximity of other family members who may help (McDonald, Dew, & Cumming, 2010). The availability of support from other sources, such as from friends or other family members, contributed to better outcomes for YCs, as they described their condition to be better than when no support was available (Polkki, Ervast, & Huupponen, 2004). Likewise, in a study by Pakenham et al. (2007), quality and quantity of support was a very strong and important predictor for adjustment; YCs with more support exhibited superior outcomes.

Being able to receive formal support services such as home help, governmental support or respite care can also be a determinant factor in how much caregiving is required within the family (McDonald, Dew, & Cumming, 2010). For instance, McDonald, Cumming, and Dew (2009) found that when formal support was limited or too expensive, families become in greater need of YCs. Thus, it is believed that young caring may not be required if the family receives adequate formal support (McDonald, Dew, & Cumming, 2010).

Individual, person-oriented caregiving factors.

It is important to question, aside from circumstance-related variables, what factors within the person could potentially explain one's caregiving role. One's age, gender, personality (temperament), or birth order can determine who is more likely to become a caregiver. Some studies have explored age and gender. Temperament and birth order are yet to be examined.

Age. The majority of studies found that YCs' average age is usually 12 (Shifren & Kachorek, 2003; Nagl-Cupal et al., 2014; Warren, 2007). Older children reported to have more caregiving tasks (Banks et al., 2002; Ireland & Pakenham, 2010; Nagl-Cupal et al., 2014; McDonald, Dew, & Cumming, 2010; Ali et al., 2012). On occasions when the older children were unavailable, the younger ones took over the role, but only if they could handle it (Ali et al., 2012; McDonald, Dew, & Cumming, 2010).

Gender. Caregiving is found to be a gendered activity among YCs as well. Eley (2004) found that it is more expected for females to take on the caregiver role and for males to adopt the disciplining role. In her sample, girls were more likely to become YCs and to be involved in domestic and personal caregiving tasks (Eley, 2004). Similarly, Joseph, Becker, Becker, and Regel (2009) claimed that females were more likely to be involved in providing personal and intimate care. Cass (2007) suggested that gender differences only begin at the age of 18-24, when females start to provide the most amount of care. However, Eley (2004) noted that it is important to consider availability; she claimed that males will provide intimate care when females become unavailable.

Studies have investigated males' contribution to care. Smyth, Blaxland, and Cass (2011) found that males experience trouble coming to terms with their caring role since it

conflicts with their notion of masculinity. Thus, males are shown to be more motivated to hide their caregiving role and be more ashamed of it (Bolas, Wersch, & Flynn, 2007). It could be argued that with greater flexibility and acceptance from certain societies, it may be easier for males to accept their caregiving roles. Hence, recent research describing gender roles in caregiving has reported mixed findings. Fives et al. (2013) found that in some families with both sons and daughters present, boys were more likely to share caregiving roles but to a lesser degree than girls. Likewise, McDonald, Cumming, and Dew (2009) found that in similar families, males and females shared an equal amount of care. Perhaps the gender difference gap with respect to caregiving is slowly closing.

Birth order. Only one study by Cassidy and Giles (2013) mentioned birth order, merely for demographic purposes. Research by Lackey and Gates (2001), who investigated retrospective accounts of adults who were once YCs, revealed that some participants indicated that in their families the siblings were most likely to share the caregiving responsibilities by deciding who would be responsible for certain tasks.

Since no other information regarding birth order in YC literature exists, corresponding findings are drawn from research on informal adult carers. Tolkacheva, Groenou, and Tilburg (2010) and Karasik and Conway-Turner (1995) found that having a greater number of siblings is beneficial since they would most likely share the caregiving roles and support each other through the process. Upon studying about the anticipation of care among pairs of siblings, birth order played a major role in acquiring the caregiving role especially when considering proximity and age factors (Karasik & Conway-Turner, 1995). Last born daughters who lived closer to the parent who required help anticipated providing more care than last born daughters who lived farther away (Karasik &

Conway-Turner, 1995). However, anticipating caregiving versus having to provide care is not the same. There is still a lack of understanding with regards to which sibling may take on the main role of trying to split the caregiving responsibilities. Moreover, there is a lack of research that would demonstrate whether the tasks get distributed equally among all the siblings regardless of birth order.

Birth order is believed to be tied to personality predispositions. In his book, Leman (1998) describes the characteristics of first, middle and last born children. He claims that first borns possess leadership and organization qualities, middle borns have secretive nature and relationship oriented attributes, and last borns come with caregiving tendencies and lovable personalities (Leman, 1998). All those qualities may explain why some children become more susceptible to caregiving than others in the family. However, since research is missing, these can only be interpreted as assumptions. More empirical research is required to understand whether these relationships truly exist and whether birth order is an important contributor to caregiving.

Temperament. To date, there is no research that has investigated caregiving and temperament. Only a few studies have mentioned that YCs may have a different personality or a more positive attitude from non-carers, which makes them more willing to help, but did not specify which traits or predispositions may influence one's caregiving tendencies (Sahoo & Suar, 2010; McDonald, Cumming, & Dew, 2009; McDonald, Dew, & Cumming, 2010).

Research regarding empathy and caring with infants or school-aged children has explored prosocial behaviours as it relates to demonstration of caregiving behaviours. Volling, Herrera, and Poris (2004) found that children with socially fearful tendencies

were more likely to help younger siblings reduce their distress, but only for the purposes of reducing their own levels of anxiety and discomfort. Surprisingly, only one's negative affect was related to increase in caregiving; caregiver's pleasure and positive affective predispositions did not increase the likelihood for caregiving behaviours (Volling, Herrera, & Poris, 2004).

When exploring temperament and gender, Hoffman (1977) found that females were able to demonstrate more prosocial behaviours than males. By also exploring age, Eisenberg et al. (1996) were able to find that shyness in younger children can hinder the quantity of prosocial behaviours; shy young children were overall less sympathetic to others. However, in very young children, easy temperaments yielded more prosocial peer responses than slow to warm up or difficult temperaments (Farver & Branstetter, 1994). In all cases, more research regarding temperament of YCs is required to better understand and explain the caregiving role.

Psychosocial factors.

There is absence of studies that have explored psychosocial factors that may explain YCs' situation and their caregiving role. Factors such as attachment, self-esteem, depression, social anxiety, loneliness, and bullying have only been examined as direct impact of being a YC. Only a few research studies that compared YCs to their non-caregiving peers found interesting differences between the two populations. For instance, Sahoo and Suar (2010) found that YCs were more anxious and depressed than their peers. Well-being was also significantly different, with YCs feeling less happy overall (Lloyd, 2013). Collins and Bayless (2013) demonstrated that YCs' self-esteem was lower than their peers'. Other comparative studies revealed that YCs were bullied more frequently

than non-YCs (Warren, 2007; Lloyd, 2013; Banks et al., 2002). YCs also preferred to be alone more often than their non-caregiving peers (Nagl-Cupal et al., 2014). It has been noted that both groups (YCs and non-YCs) had similar attachment security to mothers and fathers (Remtulla, Charles, & Marshall, 2012). Despite these findings, there are currently no studies that have attempted to examine all these factors simultaneously in one given sample. Thus, it is nearly impossible to make a YC profile because as it stands now, it would be comprised of different children from dissimilar countries, and of various ages and cultures.

Population Differences: YCs versus Non-YCs

To determine whether YCs differ from the general population, researchers in various countries have begun to examine the YC samples by comparing them to non-YCs. A total of eight studies have explored the differences between children with caregiving responsibilities and others who do not require taking care of their family members. Canadian research by Charles, Marhsall, and Stainton (2010) and Remtulla, Charles, and Marshall (2012) have found no differences between the two groups with respect to gender, ethnicity, SES, task load, beliefs, and attachment security. It is possible that YCs still struggle to identify as carers or try to refrain from believing that they are somehow different from their peers (Charles et al., 2010; Remtulla et al., 2012). Upon further examination of sample size, it was found that neither study obtained an equal number of participants in the two comparison groups. Moreover, the criteria that distinguished YCs from non-YCs remained unclear.

Other studies have found significant differences when investigating YCs' task load (and type), amount of time spent caring, and negative impacts specifically with YCs

scoring higher than non-YCs on these matters (Nagl-Cupal et al., 2014; Banks et al., 2002, Warren, 2007). However, these studies were mainly descriptive, contained small sample sizes, demonstrated poorly matched groups, and established weak generalization (Nagl-Cupal et al., 2014; Collins & Bayless, 2013; Lloyd, 2013; Banks et al., 2002; Sahoo & Suar, 2010). Most of the previous comparative studies obtained samples that had similar developmental range, with participants usually within 10-18 years of age (average age of 12).

Admittedly, there is a lack of studies that have established clear population differences with scientific rigour. Although some circumstances (that do not occur in other children's lives) may contribute to YCs' worse outcomes, no research has been done to examine various factors at once and to note YCs' unique characteristics.

The Present Study

Despite the fact that some variables have already been explored in previous literature, none of the studies have examined all of the factors simultaneously and compared them to non-YCs. Therefore, the present study aimed to expand knowledge of the Canadian YC population differences by creating a YC profile.

Chapter Three: Methodology and Procedures

This study was a part of a larger research project that examined potential impediments of caregiving and YCs' daily lived experiences. The present study conducted a secondary comparative quantitative data analysis using two previously administered questionnaires: Hear Me Now (a YC data base) and the Youth Lifestyle Choices- Community University Research Alliance (YLC-CURA; a non-YC data base). This research was mainly descriptive, comparative, and exploratory in nature.

Participants

The Hear Me Now Survey.

There were 124 recruited participants in the Niagara region. Of those, 72 were females (58.1%) and 52 were males (41.9%). They were mostly grade seven students and ranged from 8 to 18+ years of age with an average age of $M = 12$. Females were slightly older ($M_{male} = 3.83$ (12 years), $SD = 2.41$ vs. $M_{female} = 3.92$ (12 years), $SD = 2.49$) than males. In this survey, all participants were identified as YCs through family members or professionals (i.e., service providers or teachers).

Majority of YCs (80.6%) were born in Canada. With regards to their ethnicity, 29 YCs (23.4%) recognized themselves as solely Canadian, while 94 (75.8%) belonged to more than one culture ($n = 123$): Italian (11.3%), French (11.3%), British (9.7%), Latin American (9.7%), Dutch (8.9%), Native (8.9%), German (7.3%), Hungarian (4.8%), Ukrainian (4.8%), American (4%), African (3.2%), Polish (2.4%), Russian (1.6%), Chinese (.8%), and other (29%).

The YLC-CURA Survey.

This sample contained the perceptions and behaviours of youth from 39 schools in the Niagara region. Both elementary (N = 537; n_{male} = 255 and n_{female} = 279) and secondary school (N = 6715; n_{male} = 3082 and n_{female} = 3401) students were included. To account for the unequal representation of the two sample sizes, a random sample was initially drawn from older sample ($N_{Secondary\ school}$ = 991), and the two samples were merged (N_{total} = 1528). A subsequent sample was then randomly drawn to include a 124 participants who matched YCs' age, gender, and number of siblings within the family.

Majority of non-YCs (91.9%) were born in Canada. Although 40 (32.3%) were classified as being only Canadian, 75 participants (60.5%) belonged to more than one ethnicity (n = 115): British (21.8%), German (15.3%), French (10.5%), Italian (8.9%), Dutch (6.5%), Native (5.6%), Ukrainian (4.8%), Polish (3.2%), Russian (2.4%), Hungarian (1.6%), American (1.6%), Chinese (.8%), and other (14.5%).

Measures

Demographics *(both Hear Me Now and YLC-CURA)*. Questions related to one's age, gender, grade, and ethnicity were included in the questionnaire. For the purposes of the current study, only information regarding age and gender were of interest. All other variables were used solely for demographic purposes. Corresponding to the ethnicity variable on the YLC-CURA survey, African, East and West Indian, and Latin American group membership options were missing. Age on the YLC-CURA surveys started at 9 years of younger, not 8 (see Appendix A).

Caregiving *(Hear Me Now only)*. Participants responded to questions that sought to understand who they provided care for, reasons for caregiving, initial age when they

first began assisting others, and number of years their relative required care for. Respondents were either given many options to choose from or a space to write down their answers (see Appendix B). A 6-point scale was used to rate the total amount of time (in hours) that was spent on completing caregiving tasks (1 = < 1 hour to 6 = 9+ hours). Higher scores indicated a greater amount of time spent caring.

Participants were also asked about what activities were expected of them. Nine potential activities were listed. The caring responsibilities included: household tasks, meal preparation, babysitting, personal care, medical care, managing the house, translation, taking care of oneself, and other. The "self-care" item was not included in the younger survey version. Participants rated their involvement with those nine tasks on a corresponding 5-point scale (1 = Rarely to 5 = Most of the time; 0 = Does not apply). Higher scores indicated more frequent task completion. Corresponding to this section, YCs were also asked how different they thought their responsibilities were from their friends. Similarly, this was rated on 5-point Likert scale (1 = Much lower to 5 = Much higher; 0 = Does not apply). Higher scores conveyed perceptions that their own responsibilities exceeded those of their friends to a higher degree. Finally, participants were asked to fill in which formal support they currently received. A list of supports included: educational/school support, support groups, nursing services, agencies, counselling, homecare, other, and none.

Parental education- SES *(Hear Me Now and YLC-CURA)*. Participants responded to questions pertaining to the social and economic status (SES) of the parents (see Appendix C). This section assessed the level of education attained for each parent or guardian separately. Originally adapted from the YLC-CURA, participants were asked to

rate “what is the highest level of education your mother/stepmother/female guardian AND father/stepfather/ male guardian completed?” on an 8-point scale (1 = Did not complete high School to 8 = Don’t know). Higher scores signified higher educational attainment. The elementary survey versions had fewer options.

Family structure *(Hear Me Now and YLC-CURA)*. This section included six questions pertaining to family structure, birth order, and availability and proximity of other people (see Appendix D). In order to evaluate family composition, participants were asked with whom they lived. Many different options were provided (i.e., two parent households, single family, grandparents, group home, foster care, etc.). The YLC-CURA elementary version did not include three items (living on their own, in a group home, and with a roommate). Birth order was addressed by asking about the number of siblings they had and how many were younger and/or older. This was assessed on a 5-point Likert scale, where scores ranged from 0/none to 4 or more. Availability and proximity of others was evaluated by two questions: “how many other people live in your home?” (5-point Likert scale: 1 person to 7+ or more people) and “do you have other family members who live close by?” where responses simply entailed a ‘yes’ or a ‘no’.

Parental attachment quality *(Hear Me Now and YLC-CURA).* Two sections in the survey corresponded to participants’ attachment with their mother and father (see Appendix E). These questions pertained to one’s perceptions of the positive and negative aspects of relationships with his/her parents. Parental attachment, which was originally adapted from Armsden and Greenberg (1987), included 3 subscales: Trust, communication, and alienation between parents and children.

Overall, this section included 17 questions relating to each parent/guardian. Respondents scored their attachment to their mother/female guardian AND to their father/male guardian on a 4-point Likert scale (1 = Almost always or always to 4 = Almost never or never). Higher scores specified lesser attachments to their parents/guardians. A total of six items were reverse-coded; in that case opposite interpretation is appropriate. While the "Hear Me Now" older version did not include one item, the YLC-CURA elementary version did not include three items on each scale (see Appendix M).

The Cronbach's alpha for mother's trust, communication, and alienation in both samples combined was .84, .77, and .79, respectively, and for father's trust, communication, and alienation, it was .83, .81, and .77, respectively. Total attachment scores were composed of summing trust and communication, and subtracting alienation.

Friendship attachment quality *(Hear Me Now and YLC-CURA).* Participants were asked questions regarding the positive and negative aspects of the relationships with their friends. Originated from Armsden and Greenberg (1987), this section represented a shortened version of only 18 items in total. Participants responded to a 4-point Likert scale ranging from almost always or always (1) to almost never or never (4), with higher scores specifying lesser attachments to their friends and poorer quality of friendships overall (see Appendix F). It was composed of the same three subscales: Trust, communication, and alienation. Total attachment was generated by adding trust and communication, and subtracting alienation scores. Cronbach's alpha for the combined samples for trust, communication, and alienation was .88, .85, .77, respectively. One item was reverse-coded; in that case opposite interpretation is appropriate (see Appendix M).

Temperament and optimism *(Hear Me Now and YLC-CURA)*. Participants were asked to respond to various questions about their inner traits, optimism, openness, distractibility, cheerfulness, sleeping patterns, etc. In order to assess temperament, a revised version of the Dimensions of Temperament Survey (DOTS-R) was used (Windle & Lerner, 1986). Optimism was assessed using the adapted scale for Youth Leisure Study and Life Optimism Test (LOT) from Goodman, Knight, & Durant (1997).

Participants' temperament was assessed on various statements and rated on a 4-point Likert scale (1 = Almost always or always to 4 = Almost never or never). Examples of these items included 'I laugh and smile at a lot of things', 'I feel good about my future', and 'I do not like changes in routine', etc. (see Appendix G). In all cases, higher scores indicated less positive temperament or optimism on each of the items. A total of six items were reverse coded; in that case opposite interpretation is appropriate. While the Hear Me Now survey contained the full 31 item scale, both versions of the YLC-CURA did not include two items; the elementary version included 12 items in total (see Appendix M).

Overall, the temperament measure was split into seven related subscales: activity level, approach/withdrawal, flexibility/rigidity, mood, rhythmicity/sleep, task orientation/distractibility/persistence, and life optimism. The combined sample of YCs and non-YCs showed overall good reliabilities (Cronbach's alpha levels: Activity level (.74), approach/withdraw (.74), mood (.84), rhythmicity/sleep (.69), task orientation (.70)). The scale did not hold well together for the composite of optimism (LOT), thus only one item ("I expect the best") was chosen to symbolize this attribute. The composite

for flexibility and rigidity also held together poorly, thus the item "it takes me a long time to get used to new things at home" was chosen to represent this trait.

Depression *(Hear Me Now and YLC-CURA).* Participants were evaluated on the depression scale (CES-D), originally adapted from the National Institute of Mental Health (1972), that aimed to assess the degree of participants' depressive symptoms in the past two weeks. This scale focused on depressive mood and emotions, feelings of helplessness, sleep difficulties, etc. It included 20 items that were measured on a 5-point Likert scale (1 = None of the time [less than 1 day] to 5 = Most of the time [10-14 days]). Higher scores represented more depressive symptoms (see Appendix H). A total of four items were reverse coded; in that case opposite interpretation is appropriate (see Appendix M). In order to increase reliability of this composite, one item ("I felt like doing nothing") was removed, resulting in Cronbach's alpha of .86 for the combined samples. This scale was not included in the Elementary version of the YLC-CURA.

Self-esteem *(Hear Me Now and YLC-CURA).* Originated from Rosenberg (1965), The Rosenberg Self Esteem Scale was aimed to measure person's global self-esteem (i.e., worthiness, appearance, and competence). Participants were assessed on a 5-point Likert scale (1 = Strongly agree to 5 = Strongly disagree), where higher scores conveyed lower self-esteem (see Appendix I). A total of five items required reverse-coding, thus opposite interpretation is appropriate (Appendix M). This 10-item composite maintained a Cronbach's alpha of .76 for the combined samples.

Social anxiety *(Hear Me Now and YLC-CURA).* Participants responded to questions pertaining to the degree of social anxiety in their lives. This scale included three sections: fear of negative evaluations, avoidance and distress in new situations, and

avoidance and distress in general. Adapted from Ginsburg, LaGreca, and Silverman (1998), this 4-point Likert scale included 14-items that ranged from (1) almost never or never to (4) almost always or always (see Appendix J). Higher scores indicated more feelings of social anxiety. Reliabilities for the combined sample were strong, with Cronbach's alpha for fear of negative evaluation, new social avoidance and distress, and general social avoidance and distress of .93, .84, and .82, respectively.

Loneliness *(Hear Me Now and YLC-CURA).* Two measures of loneliness included individual's aversion to and affinity for being alone. Aversion to being alone corresponded to negative feelings when alone, while affinity for being alone was the preference to be alone. These measures originated from Marcoen, Goossens, and Caes (1987), who used the Louvain Loneliness Scale for Children and Adolescence (LLCA). Each scale included 8 items on a 4-point Likert scale (1 = Almost always or always to 4 = Almost never or never). Higher scores on the scale specified less aversion to and lower affinity for being alone (see Appendix K). Cronbach's alpha for the combined sample for loneliness aversion and affinity was .79 and .87, respectively. The elementary version of the YLC-CURA survey did not include three items on each scale (Appendix M).

Bullying *(Hear Me Now and YLC-CURA).* In order to assess bullying, two sets of questions examined participants' participation in bullying (acts they have inflicted upon others as perpetrators) or victimization by bullying (acts inflicted upon them). The items in each section were similar, measuring direct (i.e., physical, verbal, social, and emotional aggression) and indirect forms of bullying (i.e., daring others to do something, spreading rumors, etc.). This scale was originally adapted from Marini, Spear, and Bombay (1999). Each section produced a score that ranged from 1 (never) to 5

(everyday), where higher numbers represented a greater frequency of bullying (see Appendix L). The combined sample yielded a Cronbach's alpha of .93 for bullying that was directed at them and .88 for bullying that was done by them.

Procedure

The Hear Me Now survey.

Upon ethical clearance from Brock University Research Ethics Board, recruitment of participants was done through local agencies providing services to YCs and individuals with illnesses or disabilities. Consent forms were sent to parents of interested children and youth (see Appendix N). The parents were instructed to drop off the completed consent forms in a box located at the local agency.

Once parents and children signed the consent forms, they were invited to attend a local agency to complete the surveys as a group or individual times were arranged. Only those with signed informed consents were able to partake in this study. Before administrating the self-report questionnaires, YCs gave assent to validate that their participation was in fact voluntary (see Appendix O). In order to make sure all YCs would be able to fill the survey adequately, two versions of the surveys were administered to account for the different developmental stages of the two age groups. One survey corresponded to the younger group (ages 8-12) and another for the older group (ages 13-18). Additionally, program staff and other volunteers were available on site to assist with reading or filling in surveys for those who struggled.

Completing the questionnaires took between one and two hours. Upon completion, each participant inserted their survey into an envelope and sealed it at once. They also received a debriefing letter that restated the purpose of the study and offered

names of supporting community agencies for future reference. As a compensation for participation, pizza and drinks were offered and served on site during data collection. Additionally, their parents were entered into a draw for a Walmart gift certificate. Data have been collected since 2006.

The YLC-CURA survey.

In the year 2000, after approaching the Niagara School Boards, the YLC-CURA research team conducted pilot testing of the questionnaire. In 2001/2002, consent forms and information letters were mailed to interested parents. The elementary school survey, which was divided into two sessions, was administered in the classrooms. Anyone without consent forms was instructed to engage with alternative material such as puzzles, and other exercises that included reading and filling in related 'what if' scenarios.

In the beginning of each session, the research assistants informed students about the purposes of the study, and instructed them to begin once they filled the face sheet and consent forms. Some students had a choice of completing the questionnaire in the library. For grade 5 and 7 students, the research assistants read the questionnaire out loud. All collected information was kept confidential by placing the material into sealed envelopes. Upon completion of the first session, all students who were not finished with the questionnaire were instructed to seal their surveys shut and sign the back. They were able to complete it during the next scheduled session.

The secondary school survey administration was divided into half day or two one-hour sessions. The teachers were instructed to read a script that summarized the purpose and importance of the study. The participating students with the signed consent forms were instructed to begin the survey by completing the face sheet and the consent form.

Students who did not have consent forms were engaged with alternative material which included articles and questions about related subjects. At the end of the first session, students who did not fully complete the questionnaire signed their names on the sealed envelopes to be able to continue it in the next session. In both instances, all information was kept confidential except in cases where there was a potential for abuse. The 2001/2002 data collection was used for the secondary data comparison.

Data Analysis

Once all the surveys were completed, statistical analyses were performed using IBM SPSS statistics 22. Variables were entered into SPSS and coded accordingly. The first step entailed merging of the two YLC-CURA surveys (Elementary and Secondary survey versions). Once data were successfully merged, they were coded to match the YC sample. For instance, participants' age was recoded to start from '10 years or younger' and end at '17 years or older' to cover all the participants in the study. The second step required running frequencies on age, gender, and number of siblings in the YC sample in order to find the same participants in the YLC-CURA database. At the end, both samples were matched and merged on age, gender, and number of siblings in the family (N = 248). T-test analyses determined that the samples did not differ significantly from each other; SES was also similar in both groups, and thus not statistically significant (see Table 1). The analyses used a significance level of .05.

Table 1.

Demographic Data: Composition of Samples

		Young Carers (*n* = 124)		Non Young Carers (*n* = 124)	
Gender	Males	52 (41.9%)		52 (41.9%)	
	Females	72 (58.1%)		72 (58.1%)	
Age	10/younger	30		30	
	11	17		17	
	12	12		12	
	13	17		17	
	14	17		17	
	15	7		7	
Average	16	6		6	
	17/older	18		18	
	(12 years of age)	*M* = 3.88, *SD* = 2.45		*M* = 3.88, *SD* = 2.45	
Sibling #	0 / none	12		11	
	1 sibling	34		38	
	2 siblings	35		35	
	3 siblings	24		25	
	4 or more	14		13	
	Missing	5		2	
Average	(1 sibling)	*M* = 2.95, *SD* = 1.17		*M* = 2.94, *SD* = 1.18	
Birth Order	Oldest	34 (27.4%)		43 (34.7%)	
	Middle	34 (27.4%)		30 (24.2%)	
	Youngest	39 (31.5%)		37 (29.8%)	
	Only child	12 (9.7%)		12 (9.7%)	
	Missing	5 (4%)		2 (1.6%)	
Average	(Middle)	*M* = 2.24, *SD* = .98		*M* = 2.15, *SD* = 1.02	
Parental SES		Mothers	Fathers	Mothers	Fathers
	No High School	6 (4.8%)	11 (8.9%)	4 (3.2%)	4 (3.2%)
	High School	18 (14.5%)	17 (13.7%)	26 (21%)	17 (13.7%)
	Some Coll/ Uni	14 (11.3%)	10 (8.1%)	16 (12.9%)	14 (11.3%)
	College Dip.	13 (10.5%)	12 (9.7%)	15 (12.1%)	17 (13.7%)
	University Deg.	14 (11.3%)	7 (5.6%)	18 (14.5%)	21 (16.9%)
	Professional	9 (7.3%)	4 (3.2%)	3 (2.4%)	7 (5.6%)
	Don't know	34 (27.4%)	39 (31.5%)	29 (23.4%)	34 (27.4%)
	Still attending	0	0	3 (2.4%)	0
	Missing	16 (12.9%)	24 (19.4%)	10 (8.1%)	10 (8.1%)
Average	(Diploma)	(*n* = 108)	(*n* = 100)	(*n* = 114)	(*n* = 114)
		M = 4.93	*M* = 4.94	*M* = 4.61	*M* = 4.97
		SD = 2.45	*SD* = 2.73	*SD* = 2.37	*SD* = 2.31

Note: No significant differences were found between YCs and non-YCs on any of the above variables.

Subsequently, the data was screened for missing values. An overall summary of missing values revealed a 4.9% with missing data that ranged from the lowest, 0.0%

(Temperament: “I like trying new things”) to the highest, 10.5% (Father’s attachment: “cares about my point of view”). The missing responses for father’s attachment may be due to a higher percentage of absent fathers in YCs’ lives. There was no pattern to the missing data. There were increasingly larger percentages of missing responses towards the end of the surveys, which could be directly related to the length of the questionnaires. Since the YC sample only included 124 participants, deletion was not an option, thus it was imperative to maintain the sample size. Multiple imputation was utilized as an alternative method to estimate missing data. It was suggested to conduct five iterations (Tabachnick & Fidell, 2007). In other words, the data were scanned and estimated values for missing data five times in total. Only items that were missing at random were imputed. All other missing values that were not missing at random were deemed to be appropriately missing (i.e., variables that did not exist in all the survey versions), and thus were not imputed (Sterne et al., 2009). Again, t-test analyses illustrated that the new imputed data were not significantly different than the non-imputed data with regards to the matching criteria ($p > .05$). Even though five imputations took place, further analyses from this point on included interpretations of the first imputed data set; however, all analyses were constantly compared to the original set to maintain accuracy, quality, and integrity of results. In most analyses, the results elicited similar patterns. If any changes occurred (i.e., significant results becoming insignificant, or vice versa), they were noted.

This study required building composites for temperament, attachment, self-esteem, depression, loneliness, social anxiety, and bullying variables. Therefore, reliability analyses were conducted for the combined sample (YCs and non-YCs) and new variables were created only for those composites that held well together. Table 2

illustrates the means and standard deviations on each of the composite variables. Table 3 displays the correlations among all the composites as well as on age and gender.

Table 2.

Means and Standard Deviations for All Composite Variables

Variable	*M*	*SD*
Temp: Activity Level	2.73	.89
Temp: Approach/ withdraw	1.96	.70
Temp: Flexibility/ rigidity	2.11	.83
Temp: Mood	1.74	.66
Temp: Rhythmicity/ sleep	2.79	.86
Temp: Task orientation/ distractibility	2.28	.72
Temp: LOT (optimism)	2.13	.93
Total Attachment Mother	.63	1.79
Total Attachment Father	.95	1.83
Total Attachment Friends	.68	1.62
Self-Esteem	2.49	.67
Depression*	2.45	.68
Loneliness Aversion	2.66	.66
Loneliness Affinity	2.55	.73
Social Anxiety: Fear of negative evaluation*	2.05	.88
Social Anxiety: Avoidance and Distress new*	2.21	.86
Social Anxiety: Avoidance and Distress general*	1.87	.83
Bullying done to you*	1.68	.77
Bullying done by you to others*	1.29	.42

Note: All variables (n = 248) except: mother attachment (n = 245), father attachment (n = 220), and depression (n = 171). Total Attachments represented the summation of 'trust + communication – alienation' composites. With all measures, higher scores represented lower levels of temperamental traits, attachment qualities, self-esteem, and loneliness. *higher scores indicate more symptoms of depression, anxiety, and frequencies of bullying.

Table 3.

Correlations Between Age, Gender, and All the Composite Variables

Variable	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
1.Age	.09	.29***	-.07	.11	-.01	.37***	.18**	.34***	.33***	.13*	.14*	-.06	.12	.03	-.12	.01	-.12	-.16*	.10
2. Gender [a]	-.07	-.05	-.01	-.22***	-.12	.13*	.06	-.05	.11	-.11	.19**	.05	-.14*	.09	.08	.12	.05	-.08	-.21***
3. Temp 1	-	-.06	-.34***	.12	-.14*	-.29***	-.07	-.18**	-.21**	-.12	-.22***	-.33***	.25***	.08	-.09	-.14*	-.05	-.03	-.11
4. Temp 2		-	.05	.51***	.14*	.39***	.39***	.25***	.26***	.31***	.24***	.17*	.09	-.01	.07	.21***	.21***	-.01	.08
5. Temp 3			-	.12	.18**	.16*	.03	.17**	.15*	.16**	.22***	.27***	-.21***	-.22***	.16*	.17**	.13*	.14*	-.05
6. Temp 4				-	.09	.18**	.19**	.22***	.06	.35***	.24***	.25***	.16**	-.15*	.12	.15*	.28***	.13*	.09
7. Temp 5					-	.19**	.09	.22***	.14*	.12	.11	.17*	-.05	-.06	.12	.09	.04	.16**	.06
8. Temp 6						-	.18**	.41***	.29***	.23***	.44***	.23**	-.07	.07	-.01	.11	.03	.04	.23***
9. Temp 7							-	.18**	.21**	.27***	.17**	.24**	.06	-.05	.21***	.25***	.23***	.09	.02
10. Attach Mom								-	.60***	.35***	.39***	.39***	-.12	-.09	.13*	.11	.12	.20**	.39***
11. Attach Dad									-	.31***	.45***	.36***	-.11	-.09	.10	.12	.09	.15*	.16*
12. Attach Friend										-	.34***	.41***	.05	-.09	.23***	.25***	.32***	.19**	.08
13. SE											-	.56***	-.33***	-.15*	.16**	.24***	.19**	.19**	.06
14. DP												-	-.27***	-.23**	.54***	.44***	.43***	.36***	.13
15. Lone Aversion													-	.19**	-.11	-.06	-.02	-.11	.04
16. Lone Affinity														-	-.07	-.09	-.06	-.22***	.04
17. SA1															-	.69***	.72***	.28***	.02
18. SA2																-	.72***	.07	-.06
19. SA3																	-	.14*	-.04
20. Bullying to you																		-	.29***
21. Bullying by you																			-

Note. [a] Gender: 1 = male, 2 = female. All variables (n = 248) except: mother attachment (n = 245), father attachment (n = 220), and depression (n = 171). Temperaments: Temp 1 = Activity level, 2 = Approach/ withdrawal, 3 = Flexibility, 4 = Mood, 5 = Rhythmicity/ sleep, 6 = Task orientation/distractibility, 7 = LOT. Attach = represents total attachments (trust + communication – alienation). SE = Self-Esteem. DP = Depression. Lone = Loneliness. Social Anxiety: SA1 = fear of negative evaluation, SA2 = new social avoidance and distress, and SA3 = general social avoidance and distress. * $p < .05$. ** $p < .01$ *** $p < .00$

In order to develop a YC profile, it was essential to conduct descriptive analyses (measures of central tendency and frequencies) on YC' caregiving variables to better understand this sample. Correlational analyses were conducted to understand the relationships between caregiving and other variables in the study that included individual, family, and psychosocial factors. To address population differences, it was paramount to compare both samples on various important constructs. Multivariate (MANOVA) analyses were conducted on temperament, attachments, social anxiety and bullying. While a one-way ANOVA assessed differences on family structure, a Chi-square analysis was administered on a dichotomous variable that represented availability of others. Finally, independent sample t-tests were used to establish whether self-esteem and depression differed in the two groups. Cohen's d and Eta were used to estimate effect size.

Chapter Four: Results

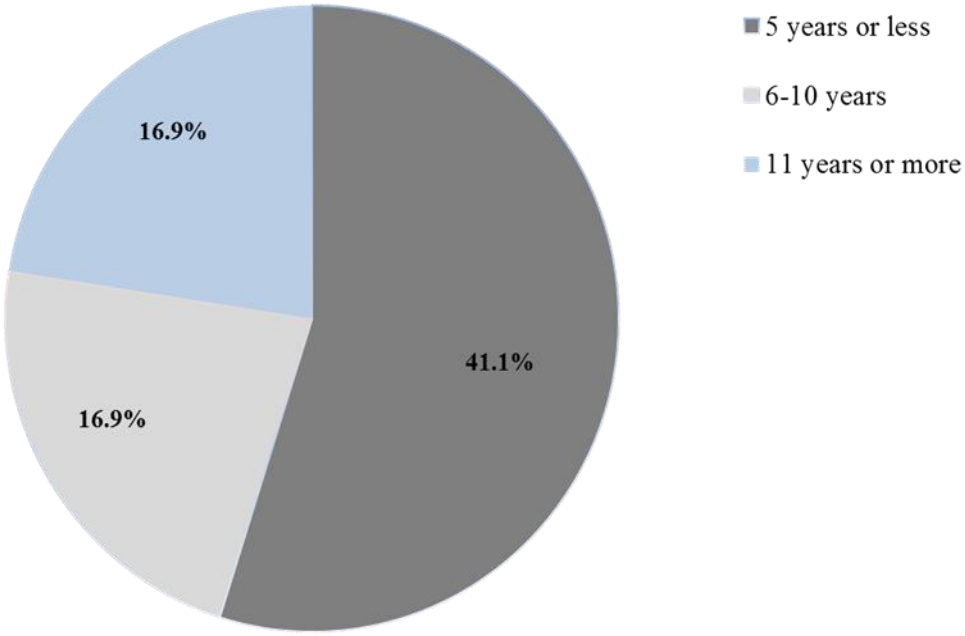
The aim of this study was to develop a comprehensive YC profile by answering three research questions:

1. Who is a young carer within the family context?
2. Are young carers different from non-young carers?
3. What does a young carer profile look like?

The results of this study intended to enhance knowledge about YCs' role within the family and promote awareness regarding this topic.

Who is a Young Carer within the Family Context?

Providing care is one prerequisite of being a young carer. In this context, YCs were asked how many years their relative required care for, and the age they were when they first began providing assistance. YCs' current age was compared to their starting point, thereby yielding a better understanding of the number of years they have been providing care for. It is illustrated in the following pie chart (see Figure 3):



Note: The following percentages do not add up to a 100% due to 25% of missing data (overall n = 124)

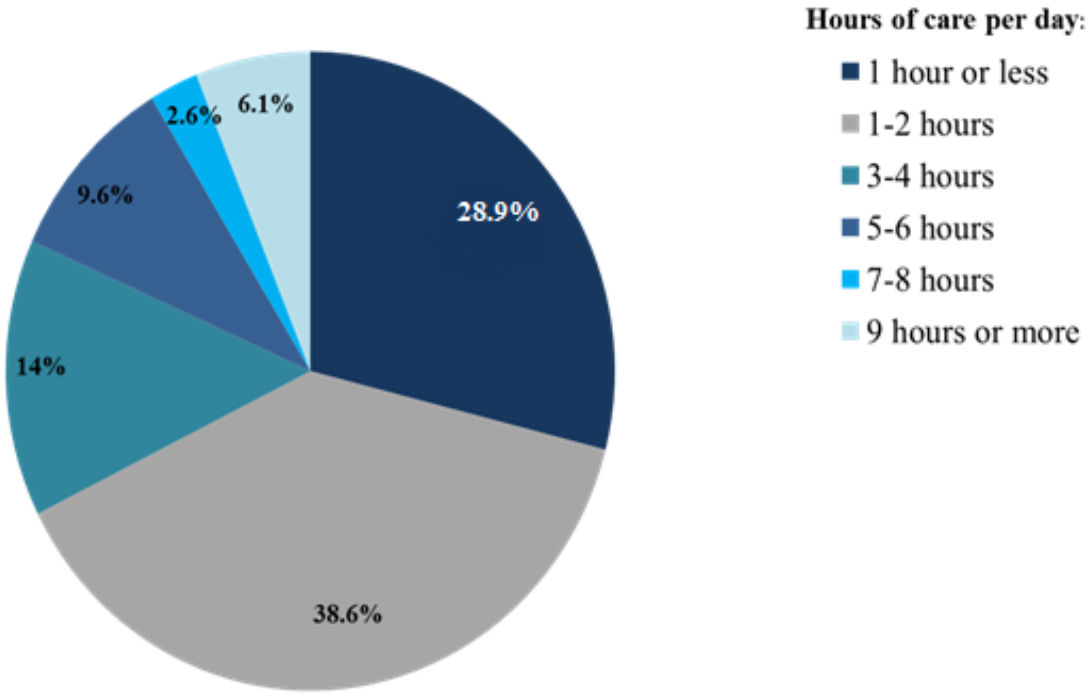
Figure 3: Years of providing care

Of the 124 YCs, 50 YCs provided care for five years or less, 21 for 6-10 years, 21 for over 11 years, and 31 had missing data. There were no significant gender differences in the years of care provision (t (122) = -.68, p = .495, Cohen's d = .13). On average, both males and females have been providing care for 6-10 years (M_{male} = 2.19, SD = 1.25, n = *52*; M_{female} = 2.35, SD = 1.24, n = 72). Males (n = 39) started to provide care around the age of 7 (M = 7.49, SD = 4.62), while females (n = 52) began to assume the caregiving role around the age of 6 (M = 6.56, SD = 4.28).

Correlational analyses revealed that there was a relationship between years of care provision and YCs' age (r = .280, p = .002, n = 124); YCs provided more care as they got older. When analyzing whether parental or friends' attachments correlated with years of

care provision, it was found that longer care was associated with weaker attachment quality to mothers (r = .195, p = .037, n = 114). Additionally, there was a positive correlation between years of providing care and the temperament trait for task orientation or distractibility (r = .178, p = .048, n = 124); longer caregiving was associated with higher scores of distractibility.

It was paramount to investigate how much time YCs spent caring for their family members. This question was assessed by asking how many hours per day they were assisting their relatives. The percentages are represented in the following pie chart (see Figure 4). While 28.9% (n = 124) spent less than one hour per day on caring, it is important to note that a little over half of the youth (52.6%) spent between one to four hours per day on providing care or helping others in their home. In addition, 18.3% of children spent anywhere from five to nine hours or more on caring per day. There were no significant gender differences with respect to the amount of time males and females spent on providing care (t (109.54) = -1.52, p = .133, Cohen's d = .28). Males (n = 48) and females (n = 66) cared for an average of one to two hours per day (M_{male} = 2.15, SD = 1.24; M_{female} = 2.53, SD = 1.47). A total of 10 YCs (8.1%) represented missing respondents.



Note: The following chart represents valid percentages that do not account for missing data (n = 124).

Figure 4: Amount of time spent caring in hours per day

Correlational analyses established a relationship between the amount of caring per day and the availability of others who lived nearby (r = .240, p = .012, n = 108); it was found that YCs spent more hours on caregiving when they did not have any family members living in close proximity to them who could otherwise offer some support. There were no correlations between amount of time spent caring and birth order (r = -.064, p = .507, n = 110) or number of siblings within the family (r = .096, p = .321, n = 110).

Considering that some YCs provide significant amount of assistance and that caregiving takes place within the family, it was essential to understand who these children provided care for. The following figure represents YCs' care recipient(s):

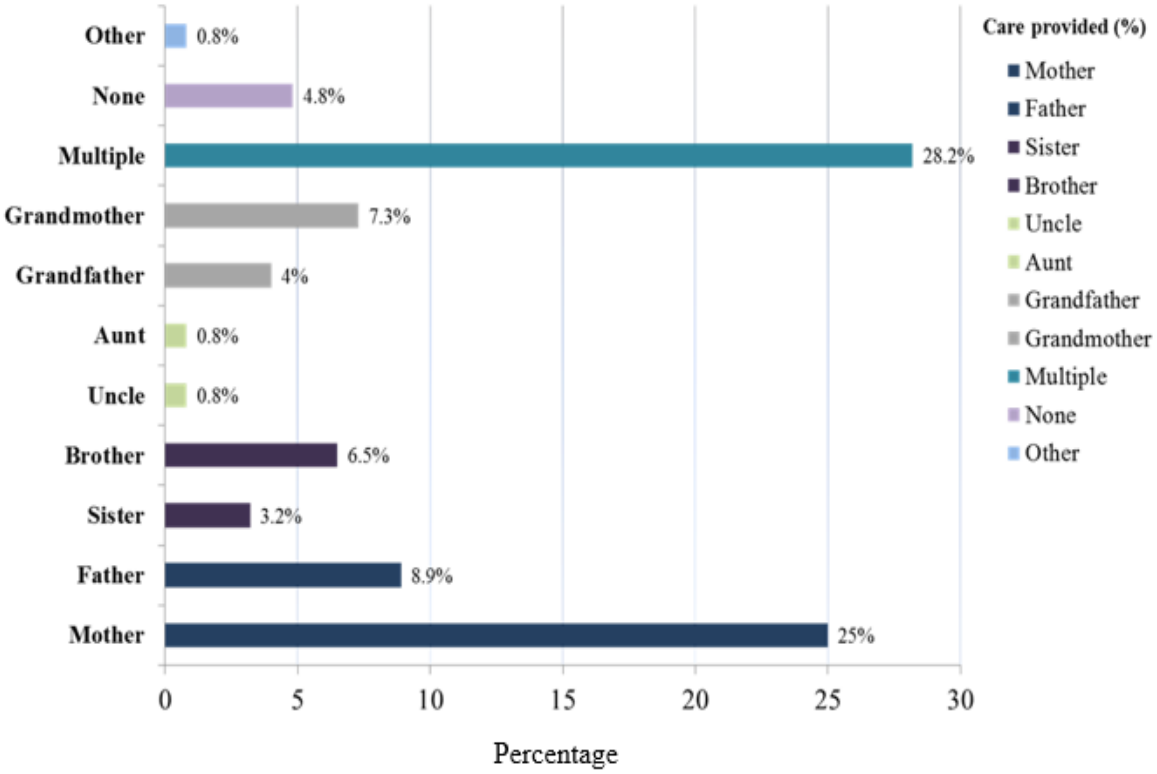


Figure 5: Care recipients

Figure 5 illustrates that 35 YCs (28.2%) provided care for multiple people in their family (*n* = 112). Taken together, 33.9% of YCs provided care for their parents, 11.3% for their grandparents, 9.7% for their siblings, and 1.6% assisted their aunts and uncles. In addition to the 12 who had missing data (9.7%), six YCs (4.8%) specified that they do not provide care for anyone in their family and one YC (.8%) chose the option for "other".

There were several reasons why YCs took care of their loved ones. The most frequent responses included (*n* = 99): Language (10.5%), Alzheimer's (9.7%), Multiple Sclerosis (9.7%), Depression (6.5%), Autism (5.6%), Brain Injury (3.2%), and Cancer (3.2%). Other less common responses included the following reasons:

Disability (2.4%), Epilepsy (1.6%), Physical Disability (1.6%), Age (either too young/old, 3.2%), Head Injury (1.6%), Down syndrome (1.6%), Diabetes (1.6%), ADHD (1.6%), Car Accident (1.6%), Unknown Disease (1.6%), and Stroke (1.6%). Although 25 YCs (20.2%) did not fill in any reason for their caregiving, 60.5% (n = 75) reported one reason of care. There were even accounts for a second (11.3%, n = 14), a third (7.2%, n = 9) and a fourth (.8%, n = 1) reason for caregiving.

YCs' provision of care may be due to several reasons that may require different levels of attention, thus it was vital to recognize what they did on a day-to-day basis. They were asked about their expected responsibilities at home that included household tasks, meal preparations, babysitting siblings, personal or medical care, house management, translation, and self-care. YCs also noted whether they thought their responsibilities were any different (higher, same, or lower) than those of their peers. Table 4 displays descriptive statistics for each responsibility and YC's perceptions of how each task compares to their perception of their friends' responsibilities. There were absolutely no gender differences with respect to the type of responsibility expected of males and females (F (8, 22) = .49, p = .844, Wilk's Λ = 0.85, partial η^2 = .15). It was also evident that in almost all cases, YCs believed that they had more workload than their peers. However, it is important to note that there were high percentages (ranging from 8.9% to 66.1%) for the "does not apply" option, that may suggest that YCs' knowledge of their peers' responsibilities may be limited to the most popular tasks such as completing household tasks, preparing meals, or babysitting.

Table 4.

Caregiving Tasks and Their Comparison to Friends' Level of Responsibility

	Expected to help 'most of the time' + 'usually' with the following responsibilities:				Compared to friends, this responsibility is 'much higher' + 'higher':			
Responsibilities	*N*	*M*	*SD*	Frequency (%)	*N*	*M*	*SD*	Frequency (%)
House tasks	122	3.69	1.48	81 (65.3%)	118	3.13	1.46	52 (41.9%)
Meal prep	119	2.81	1.46	40 (32.2%)	118	3.03	1.66	52 (42.0%)
Babysitting	118	1.47	1.72	21 (17.0%)	118	1.84	1.91	28 (22.6%)
Personal care	119	1.05	1.62	17 (13.8%)	116	1.69	2.05	32 (25.8%)
Medical care	119	1.47	1.81	25 (20.2%)	114	1.85	2.04	35 (28.2%)
Manage house	119	.76	1.32	8 (6.4%)	117	1.06	1.78	20 (16.2%)
Translation	120	1.43	1.86	27 (21.8%)	113	1.46	1.98	23 (18.5%)
Self-care	35[a]	3.57	1.54	20 (16.1%)	115	3.16	1.52	48 (38.7%)

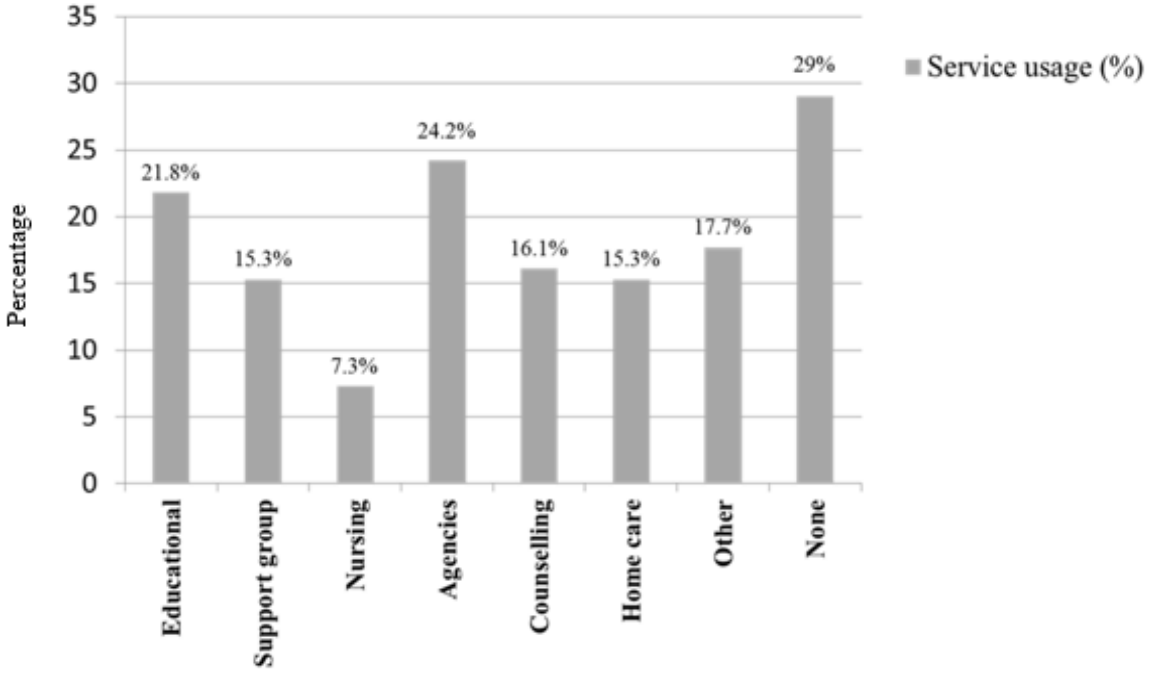
Note: [a] The self-care variable was not included in the older survey version, thus response rate is very low (n = 35). No significant gender differences were found among any of the specified responsibilities that YCs were expected to complete. For interpretations of means and standard deviations, higher scores represented higher frequencies.

Correlational analyses were conducted to assess the nature of YCs' responsibilities. It was revealed that amount of time spent caring per day was correlated with household tasks (r = .247, p = .009, n = 111) and personal care (r = .230, p = .015, n = 111); YCs spent more time caring per day when they completed more household tasks or provided personal care. YCs' age was associated with household tasks (r = .193, p = .033, n = 122) and meal preparation (r = .292, p = .001, n = 119); as YCs became older, they were more likely to complete extra household tasks or prepare additional meals. Availability of others was correlated with babysitting (r = .256, p = .008, n = 106) and self-care (r = .363, p = .038, n = 33); YCs supervised their siblings or completed more self-care when there were no other relatives living nearby.

Certain tasks were related to bullying behaviours; there were more frequent bullying incidents towards YCs who were babysitting (r = .198, p = .038, n = 111) or providing personal care (r = .188, p = .040, n = 119), but less bullying when they were completing household tasks (r = -.195, p = .032, n = 121). There were higher bullying incidents by YCs towards others when they were carrying out personal (r = .288, p = .002, n = 112) or medical care (r = .210, p = .025, n = 113), or managing the household (r = .200, p = .034, n = 112).

While household management was associated with lower levels of social anxiety (avoidance and distress (new): r = -.231, p = .016, n = 108), medical care was related to higher levels of social anxiety (fear of negative evaluations: r = .213, p = .028, n = 107). Translation was correlated with better LOT measure of temperament (expecting the best: r = -.260, p = .004, n = 120). Finally, meal preparation was associated with further alienation from friends (r = -.239, p = .014, n = 105) and mothers (r = -.194, p = .042, n = 111).

Since some families' condition may be more adverse and critical than others', they may require greater amount of assistance from outside sources. YCs were asked about the support they received. Thus, figure 6 depicts the percentage of usage for each service. The responses were as follows (n = 112): 27 acquired educational support, 19 went to support groups, 9 used nursing services, 30 went to specialized agencies, 20 received counselling, 19 acquired homecare, and 22 indicated "other" forms of support. It is important to note that 36 YCs (29%) indicated that they received no other help from any of the services.



Note: Services included support for the individual who provided care, person who required care, and for the rest of the family. Participants chose more than one resources, thus the percentages do not add up to 100%.

Figure 6: Types of support received

Service usage was correlated to amount of time spent caring and years of care provision (n = 105). For instance, amount of time was correlated with support groups (r = .206, p = .035) and nursing (r = .328, p = .001); in both cases, YCs who spent more time caring per day were more likely to report that their family used support groups or nursing services. Services such as specialized agencies, nursing, and counselling were associated with years of providing care (n = 112). YCs who provided prolonged care were more likely to state that their family received less support from agencies (r = -.239, p = .011) and nursing (r = -.236, p = .012), but more aid from counselling services (r = .208, p = .027).

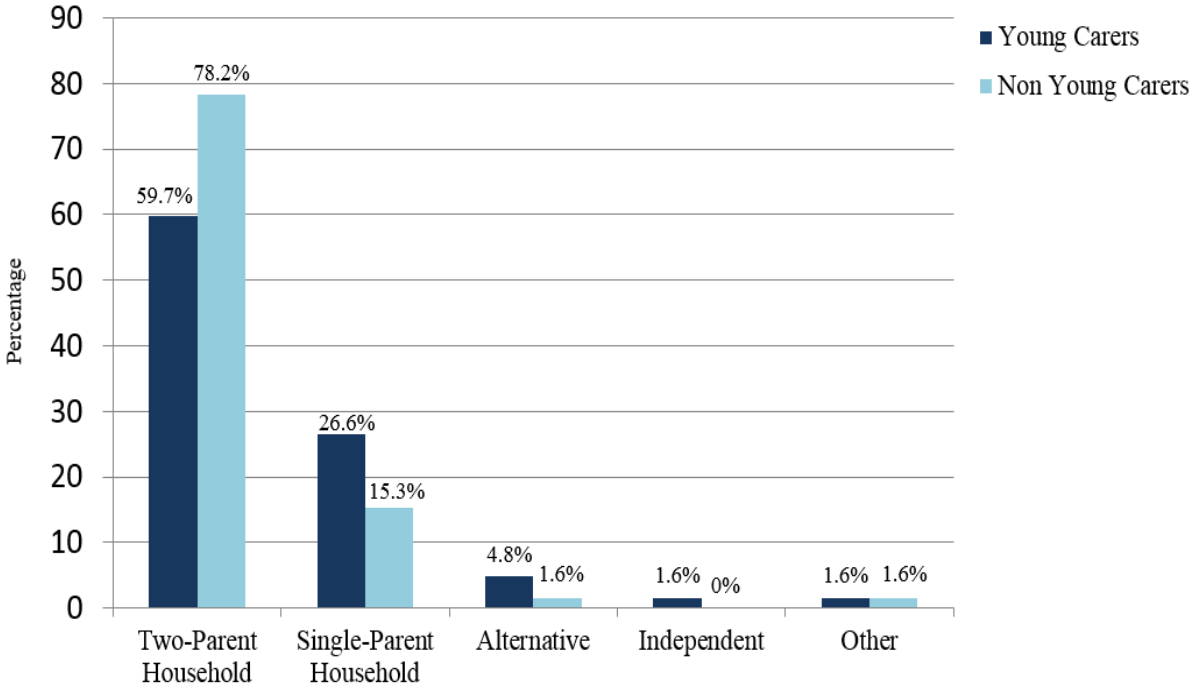
Population Differences: Are Young Carers Different from Non-Young Carers?

In order to assess whether YCs were different from their peers, it was essential to measure YCs' living conditions, attributes, and other psychosocial factors in order to build a complete understanding of what (if anything) makes YCs unique.

Family structure and proximity of others.

Living conditions may vary between YCs and non-YCs. Therefore, YCs' family households/ structures and availability of others nearby was compared to non-YCs'. A one-way ANOVA analysis revealed that YCs' family composition was significantly different from non-YCs' households with a large effect size (F (1, 235) = 6.56, p = .011, η^2 = .16). YCs were less likely to live in two parent households (M_{YCs} = 1.50, SD = .82) than non-YCs (M_{NonYCs} = 1.26, SD = .65). As represented in Figure 7, a higher percentage of YCs lived in single parent households.

Chi square analysis showed no statistically significant differences between YCs and non-YCs on whether or not they had other family members living nearby (χ^2 (1, n = 237) = 1.23, p = .269, η^2 = .07). Despite insignificance, it is worth noting that a higher percentage of family members lived near non-YCs (53.1%, n = 120) compared to YCs (46.9%, n = 117).



Note: Two parent households consisted of birth parents/ blended families; single parent households included a mother or a father-headed family; alternative households included living with foster/ adopted parents, grandparents/ relatives, or in a group home; independent living consisted of living alone or with a roommate. Significant differences were found among the two parent households.

Figure 7: Family composition

Psychosocial factors.

Temperament. Multivariate ANOVA analyses (MANOVA) were conducted to compare YCs to non-YCs on several temperamental qualities, where lower scores represented higher levels of specific temperamental attributes. Results indicated that YCs were different than their non- YC peers with respect to several temperamental traits (F (7, 240) = 7.02, p = .000, Wilk's Λ = 0.83, partial η^2 = .17). The effect was of large size.

When investigating general activity level, YCs showed slightly more movement than non-YCs (F (1, 246) = 7.55, p = .006, partial η^2 = .03), with a small effect size; YCs had a harder time sitting still and got more restless and fidgety (M_{YCs}= 2.58, SD = .86;

M_{NonYCs} = 2.88, *SD* = .91). There were statistically significant differences in approach and withdrawal characteristics, with a moderate to strong effect size (*F* (1, 246) = 18.28, *p* = .000, partial η^2 = .07), where YCs were more withdrawn and were overall less likely to be interested in new things or people (M_{YCs}= 2.14, *SD* = .67; M_{NonYCs} = 1.77, *SD* = .68). Flexibility and rigidity were also significantly different between the two groups and showed a small effect size (*F* (1, 246) = 7.81, *p* = .006, partial η^2 = .03), with YCs taking a longer time than non-YCs to get used to new things at home (M_{YCs}= 2.26, *SD* = .95; M_{NonYCs} = 1.97, *SD* = .66).

With regards to mood, the two groups were significantly different (*F* (1, 246) = 13.89, p = .000, partial η^2 = .05), with a small to moderate effect size. YCs showed slightly lower levels of cheerfulness and smiling (M_{YCs}= 1.88, *SD* = .65) than their non-YC peers (M_{NonYCs} = 1.58, *SD* = .64). Levels of rhythmicity and sleep were also statistically and significantly different in the two groups, showing a small effect size (*F* (1, 246) = 4.46, *p* = .036, partial η^2 = .02) with YCs displaying marginally less organized sleep/awake cycles (M_{YCs}= 2.91, *SD* = .78) than non-YCs (M_{NonYCs} = 2.67, *SD* = .93). Moreover, statistically significant differences were revealed in the levels of task orientation, persistence, and distractibility with a moderate to large effect size (*F* (1, 246) = 26.51, *p* = .000, partial η^2 = .09); YCs exhibited lower levels of task orientation, less persistence, and more distractibility, thereby showing less focus overall (M_{YCs}= 2.51, *SD* = .53; M_{NonYCs} = 2.06, *SD* = .81). Finally, there were no statistically significant differences in life optimism (*F* (1, 246) = .01, *p* = .920, partial η^2 = .00); YCs and non-YCs were equally expecting the best out of life.

Attachment quality. Attachments to mother, father, and friends were analyzed via MANOVA. Measures of attachment consisted of trust, communication, and alienation, where lower scores represented better quality of those attachments. Results indicated significant differences between YCs and non-YCs in their attachments to their mother (F (3, 241) = 3.46, p = .017, Wilk's Λ = 0.96, partial η^2 = .04) with a small to medium effect size, father (F (3, 216) = 5.86, p = .001, Wilk's Λ = 0.92, partial η^2 = .07) with a medium effect size, and friends (F (3, 244) = 6.79, p = .000, Wilk's Λ = 0.93, partial η^2 = .07) with a medium effect size.

Trust of mother was significantly different in the two groups, showing a small effect size (F (1, 243) = 7.41, p = .007, partial η^2 = .03); YCs trusted their mother slightly less than non-YCs (M_{YCs}= 1.84, SD = .69; M_{NonYCs} = 1.61, SD = .66). There were also statistically significant differences in the quality of communication with the mother (F (1, 243) = 8.99, p = .003, partial η^2 = .04), where the effect was of small size; YCs showed lower levels of confiding in their mothers than non-YCs (M_{YCs}= 2.10, SD = .72; M_{NonYCs} = 1.83, SD = .71). Although alienation was not statistically different between the two groups (F (1, 243) = .76, p = .382, partial η^2 = .00), YCs and non-YCs experienced significantly different levels of overall attachment to their mothers (F (1, 243) = 6.67, p = .010, partial η^2 = .03), with a small effect size; YCs exhibited higher total scores, indicative of a lower quality of attachment as a whole (M_{YCs}= .93, SD = 1.82; M_{NonYCs} = .34, SD = 1.72).

Attachments to fathers showed statistically significant differences in all tested areas. YCs and non-YCs scored significantly differently on trust of father (F (1, 218) = 17.02, p = .000, partial η^2 = .07) and the effect was of medium size; YCs trusted their

father considerably less than non-YCs (M_{YCs}= 2.00, *SD* = .69; M_{NonYCs} = 1.62, *SD* = .66). The quality of communication with fathers was also significantly different between the two groups, yielding a small effect size (*F* (1, 218) = 9.19, *p* = .003, partial η^2 = .04); YCs showed slightly less desire to confide in their fathers than their non-caregiving peers (M_{YCs}= 2.35, *SD* = .80; M_{NonYCs} = 2.02, *SD* = .82). Although alienation was not statistically significant in the original sample (*F* (1, 207) = 2.22, *p* = .138, partial η^2 = .01), the imputed data showed statistical significance (*F* (1, 218) = 6.18, *p* = .014, partial η^2 = .03) with a small effect size; YCs reported significantly higher frequencies of negative feelings towards their fathers (M_{YCs}= 2.89, *SD* = .69) than non-YCs (M_{NonYCs} = 3.11, *SD* = .65). This difference could be attributed to the fact that a greater number of YCs in the sample had absent fathers. Analyses of an overall attachment indicated statistically significant differences and a medium effect size (*F* (1, 218) = 15.32, *p* = .000, partial η^2 = .06); overall, YCs displayed a lower quality of total attachment to their fathers than non-YCs (M_{YCs}= 1.46, *SD* = 1.73; M_{NonYCs} = .52, *SD* = 1.80).

Assessments of YCs' friendship quality revealed that trust was significantly lower in YCs than in non-YCs (*F* (1, 246) = 15.23, *p* = .000, partial η^2 = .06; M_{YCs}= 1.93, *SD* = .69; M_{NonYCs} = 1.62, *SD* = .57). The effect was of medium size. There were also statistically significant differences with regards to their communication level with friends (*F* (1, 246) = 19.51, *p* = .000, partial η^2 = .07), with a medium effect size; YCs communicated with their friends about their feelings and troubles less often than non-YCs (M_{YCs}= 2.31, *SD* = .76; M_{NonYCs} = 1.89, *SD* = .70). Although alienation was not statistically different in the two groups (*F* (1, 246) = 2.41, *p* = .122, partial η^2 = .01), total friends' attachment was (*F* (1, 246) = 18.24, *p* = .000, partial η^2 = .07), and with a

medium effect size, YCs revealing lower quality of overall attachments to their friends than their non-caregiving peers (M_{YCs}= 1.11, *SD* = 1.69; M_{NonYCs} = .26, *SD* = 1.42).

Self-esteem. An independent sample t-test revealed that YCs were significantly different from non-YCs on the measure of self-esteem (*t* (160.94) = 8.57, *p* = .000). When lower scores represented higher self-esteem, YCs in general scored higher, thereby displaying lower levels of self-esteem (M_{YCs}= 2.82, *SD* = .31) than non-YCs (M_{NonYCs} = 2.17, *SD* = .78). The effect size (Cohen's *d* = 1.09) was large.

Depression. Since the elementary survey version did not contain a depression scale, the analyses were conducted on older children only (i.e., those who completed the older version questionnaires; 61 YCs and 47 non-YCs, *n* = 108). An independent sample t-test found that YCs scores on the depression scale were significantly different than their non-YC peers (*t* (100) = 3.68, *p* = .000), with higher scores indicative of higher levels of depressive symptoms. YCs scored higher than their peers; they felt slightly more depressed than non-YCs (M_{YCs}= 2.59, *SD* = .61; M_{NonYCs} = 2.11, *SD* = .79). The effect size (Cohen's *d* = .74*)* was moderate to large

Loneliness. After investigating aversion to and affinity for being alone, results from the MANOVA analyses signified that these measures of loneliness were not significantly different between YCs and non-YCs (*F* (2, 245) = .47, *p* = .622, Wilk's Λ = 0.99, partial η^2 = .00). Depending on how they felt, both groups reported that they either preferred to be alone or chose to see others when desired.

Social anxiety. Differences between YCs and non-YCs were assessed on the social anxiety scale that consisted of fear of negative evaluations, new social avoidance and distress, and general social avoidance and distress. Analyses of MANOVA indicated

there were no statistically significant differences between YCs and non-YCs on measures for social anxiety (F (3, 244) = 1.95, p = .122, Wilk's Λ = 0.97, partial η^2 = .03). Both groups experienced same levels of social anxiety, especially when they were required to see others, but once in a group, they were never too shy to interact.

Bullying. MANOVA analyses assessed whether YCs and non-YCs differed with respect to bullying behaviour that was either inflicted upon them or directed towards others. There were no statistically significant differences between YCs and non-YCs with respect to bullying (F (2, 245) = 2.63, p = .074, Wilk's Λ = 0.98, partial η^2 = .02). Both groups were either bullied or bullied others. Results trended towards significance around bullying that was directed at them (F (1, 246) = 2.94, p = .088, partial η^2 = .02), with a small effect size; YCs could potentially be at a higher risk for being bullied more often than their peers (M_{YCs}= 1.76, SD = .85; M_{NonYCs} = 1.59, SD = .69).

What Does a YC Profile Look Like?

Based on this study's findings, YCs constituted a unique population of children and youth that require further attention from research and practice. Since gender, age, and number of siblings within a family were matched in both groups, all similarities and differences could have been attributed to the caregiving role that distinguished YCs from non-YC. Matching YCs to the normal population enabled more complex simultaneous comparisons of family, individual, and psychosocial characteristics.

A YC profile was created by combining family-oriented factors (i.e., SES, availability/ proximity of others, and family structure), individual factors (i.e., temperamental attributes), and psychosocial factors (i.e., loneliness, social anxiety, bullying, attachment quality, depression, and self-esteem) (see Figure 9). Based on the

results specified above, many similarities and differences were established. For instance, SES, proximity of others, life optimism, loneliness, social anxiety, and bullying factors were not significantly different when comparing YCs to non-YCs, thus showing resemblance on these factors. Conversely, the two groups showed many differences with respect to their family structure, all other temperamental attributes, qualities of attachments with parents and friends, reports of depressive symptoms, and evaluations of self-esteem. In all cases, YCs exhibited worse outcomes. Bullying showed a trend towards a statistical significant difference and thus was placed in between the rows for similarities and differences (see Figure8).

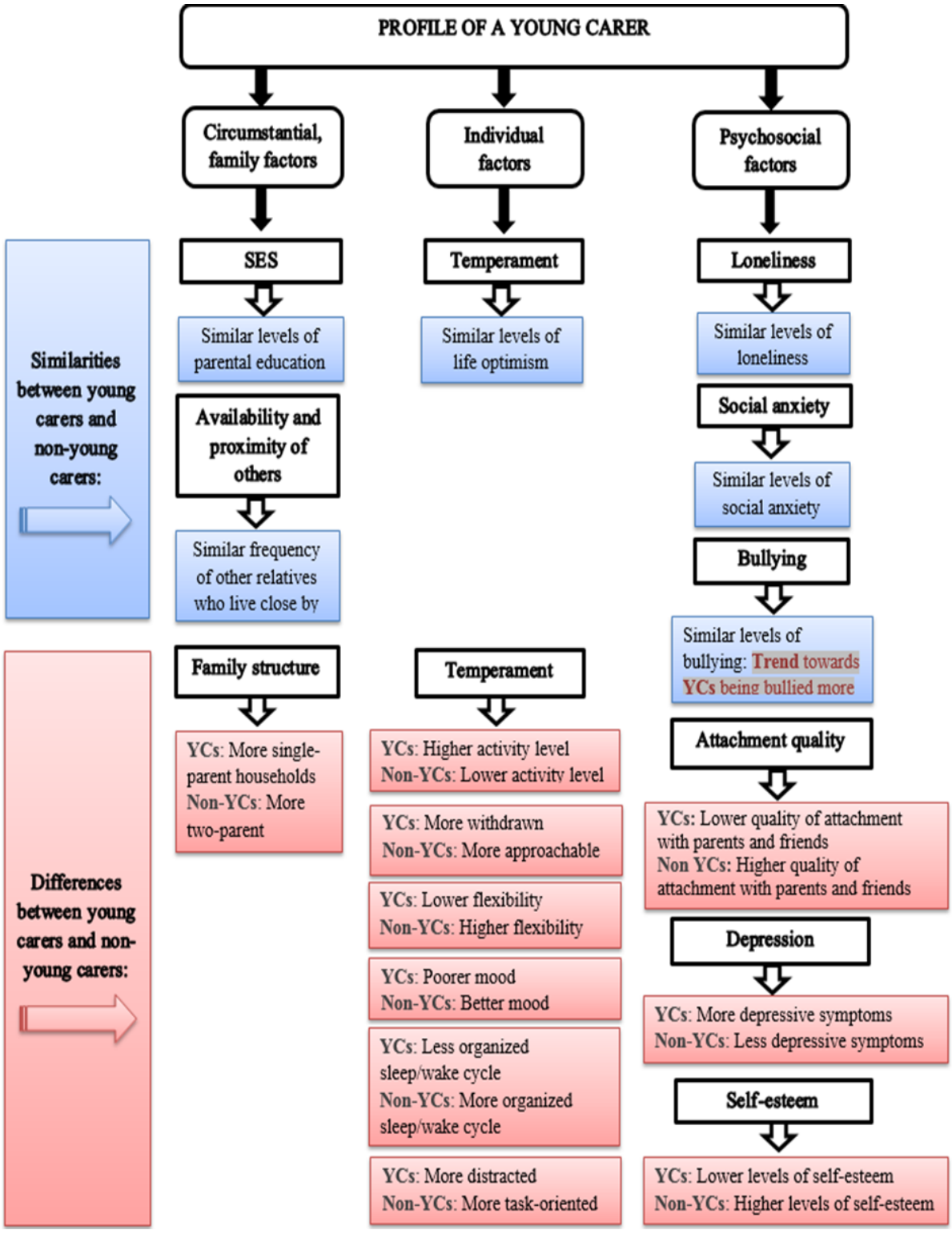


Figure 8: A young carer profile

Chapter Five: Discussion

Research about YCs in Canada is still in its early stages. Waugh et al. (2015), who examined the gap between YCs' existence and Canadian support, concluded that "Canada is lagging behind other countries in recognizing and supporting young carers" (p. 16). Moreover, there have been no previous studies that examined multiple factors simultaneously in order to understand the YC phenomenon and what makes them a unique population. The purpose of this study was threefold: to describe the YC population, to compare it to non-YCs, and to build a YC profile.

Descriptions of YCs within the Family

Findings from this study suggested that 41.1% of YCs cared for five years or less. Given that YCs' average age was 12, it should be noted that caregiving was likely to be initiated in early childhood. Specifically, girls and boys assumed the caregiving role around the ages of six and seven, respectively. On the other hand, 16.9% of YCs cared for 11 years or longer. This may indicate that some YCs were socialized into this role and were obligated to provide care since infancy. This is consistent with findings from a study by Smyth, Cass and Hill (2011) who stated, that in their sample, three pathways to caregiving were present: being born into the caregiving role, gradually increasing the amount of caregiving with time, or having a sudden shift towards caregiving. Findings by McDonald, Dew, and Cumming (2010) illuminated that caregiving became second nature especially when children got socialized into this role from a very early age. Thus, it is evident from the present study that caregiving may be a response to various familial needs; it may be required and thereby acquired from birth, early childhood, or even during adolescence, depending on the differentiating circumstances that YCs experience within their family or the onset of the health concern.

Slightly over half of YCs in this study (52.6%, *n* = 124) responded that they cared for one to four hours per day, which is the equivalent of caring for 7-28 hours per week. In some cases, 18.3% of the YCs in this study claimed that their caregiving took 5 to 9 hours (or longer) per day, which corresponds to spending over 35 hours per week on caregiving alone. These findings complement previous studies that established similar trends in the amount of time spent on caregiving (Banks et al, 2001; Nagl-Cupal et al., 2014; Moore, McArthur, & Morrow, 2009). Thus, it could be argued that caregiving may become YCs' part time work, and in extreme cases, it could evolve into full time (unpaid) labour. In the present sample, children's average age was only 12 years. Given their extent of caregiving, many interferences (e.g., to their temperaments, attachments, etc.) may begin at an early age, and by the time they enter high school, some may face increased amounts of stress.

In research that investigated the quantities of caregiving, providing 1 to 5 hours of caring per week was shown to increase well-being and happiness scores in an older sample of informal carers (Hoefman et al., 2013; Campen et al., 2013). However, YCs spend more time on caregiving (between 7-27 hours per week) and therefore the longer durations of time may cause various impediments to their developmental trajectories (Banks et al., 2001; Nagl-Cupal et al., 2014; Warren, 2007; Cree, 2003). Moreover, a common finding that this study maintained with previous literature was that as children got older, caregiving increased in amount of time (i.e., hours per day) and duration (i.e., years) (Ali et al., 2012; Banks et al., 2002; McDonald et al., 2010; Ireland & Pakenham, 2010; Stamatopoulos, 2015). Cree's findings (2003) suggested that as caregiving increased with age, YCs' reports of problems increased. In the current study, YCs spent a

significant amount of time on caregiving. Some provided prolonged care (i.e., especially those who have been carers for 11 years or longer and who spend 5 to 9 hours [or longer] on caring per day). As suggested by previous research (Ali et al., 2012; Warren, 2007; Banks et al., 2001) it was expected that many of the YCs who provided this prolonged care would show negative outcomes (i.e., decrease in social involvement, increase in bullying and psychological impact). Specifically to this sample, prolonged caregiving was associated with increased distractibility and weaker quality of attachment to mothers.

In the present study, a quarter of the YC sample (25%) cared for their mother. This is not surprising given that other studies by Shifren and Kachorek (2003) and Ireland and Pakenham (2010) demonstrated comparable findings. Given that more YCs lived in single parent families, and a large percentage of mothers required care, there were limited opportunities in which other people may assist with the caregiving responsibilities. Some YCs (28. 2%) reported taking care of multiple people within their family, which may become harder as it was usually done due to multiple reasons. This could potentially add to the amount of time YCs spend on caregiving for their loved ones. Additionally, there were many reasons for caregiving that included mental illnesses, accidents, substance abuse, behavioural and physical disabilities, etc. Again, these findings illustrated that caregiving was dependent upon diverse familial circumstances and needs. Many different situations may necessitate prolonged caregiving, thereby increasing the risk for more problems.

This study found that caregiving increased when there was no one else available to help. This was also exemplified in McDonald, Cumming, and Dew's research (2009) who noted that the YC phenomenon could exist due to the absence of others nearby.

These researchers claimed that "adequate external support is thus a critical mechanism for reducing the need for young caring" (McDonald, Dew, & Cumming, 2010, p. 464). Despite the fact that many YCs indeed received services and specific assistance for the whole family, 29% noted that they did not use any of the available support. Even though this study did not investigate the reasons behind not using the offered supports, Waugh et al. (2015) noted that services within Canada are still not targeting YCs specifically due to the lack of awareness and inadequate resources to help them. Thus, it may come as no surprise that under some circumstances, such as unavailability of others or insufficient support systems, YCs may need to spend greater amounts of time and effort to take care of others.

The current study demonstrated that the majority of YCs (71%) used some services (at least one) for themselves or for their family members. The type of service usage was correlated with the amount of time spent caring and years of care provision. YCs who spent more time (i.e., hours per day) or duration (i.e., years) on caring were more likely to use various services (e.g., support groups, nursing, specialized agencies, and counselling), but over time they relied on them less. Counselling was the only service YCs used as they got more involved in caregiving. This suggests that more services may be used at the beginning, in times of uncertainty and change, but as time elapses and YCs become more confident in their role as carers, more counselling is then required.

Many previous studies have demonstrated that undertaking caregiving responsibilities may lead to poorer health outcomes, educational difficulties, lower life satisfaction, greater behavioural problems, and decreased opportunities for socialization (McDonald, Cumming, & Dew, 2009; Fives et al., 2013; Ireland & Pakenham, 2010;

Joseph et al., 2009; Nagl-Cupal et al., 2014; Warren, 2007). Although this study did not directly investigate such influences, many responsibilities were found to correlate with bullying, social anxiety, and quality of attachments. For instance, bullying was a very serious consequence that some YCs endured. Previous studies noted that YCs were often bullied due to their caregiving roles at home (Earley et al., 2007; Moore et al., 2009; Warren, 2007; Cluver et al., 2012). Specifically to this study, there were more frequent bullying incidents towards YCs who were babysitting or providing personal care, but less bullying when they were completing household tasks. This could be related to how certain tasks may restrict YCs' time that they spend with others, thereby making them more socially distant and different. Additionally, the present study found that there were more frequent bullying incidents by YCs towards others when they were carrying out personal or medical care, or managing the household. This could be related to the heightened stress levels that these tasks may elicit. Ali et al. (2012) noted that some YCs in their sample had many emotional outbursts towards others at school, and Collins and Bayless (2013), who compared them to non-YCs, revealed they had more peer problems overall.

Certain tasks were correlated to social anxiety; while household management was associated with lower levels of social anxiety, medical care was related to higher levels of social anxiety. This could be related to societal norms; certain tasks may elicit more social anxiety due to inconsistencies with what may be perceived as 'normal'. For instance, children's medicine administration may be deemed as far more unacceptable than household management. Thus, it may elicit more social anxiety overall, as YCs may fear more negative evaluations from others upon completing this kind of task.

Furthermore, meal preparation was associated with greater alienation from friends and mothers. This could be explained by the fact that meal preparation often takes a long time which could limit their involvement with their friends and family. However, due to an absence of studies, future research should investigate these links further to establish more valid and sound conclusions.

This study found that, in some cases, YCs thought that their responsibilities exceeded their friends', especially with reference to household, meal preparation, and self-care tasks. Smyth et al. (2011) also demonstrated that once YCs knew about their peers' responsibilities at home, they were more likely to respond that they were completing more tasks than their friends. Similarly, in two comparative studies, it was found that in almost all cases, YCs completed a greater number and type of tasks than their peers (Nagl-Cupal et al., 2014; Warren, 2007). This contradicted another comparative study that claimed that YCs did not perceive their workload to be any different than their peers (Remtulla et al., 2012). In the current study, all expected responsibilities (i.e., household tasks, meal preparation, babysitting, medical care, personal care, translation, and house management) have yielded an increasing frequency of the "does not apply" response, ranging from 8.9 % (for household tasks) to 66.1% (for house management); this could be due to the fact that YCs may not be aware of the type of tasks their friends complete at home. Only the most popular tasks such as household, meal preparation, and babysitting, may be known and be talked about explicitly.

The idea regarding "who will provide the most caregiving within the family?" has been researched extensively. The two main assumptions that are predominant in the literature is that females and oldest children provide more care within the family.

Although it could be true that caregiving may be viewed as a gendered activity, this study demonstrated that there were absolutely no statistically significant differences in the amount or type of care males and females provided. Comparable to findings from Cass (2007), males and females spent similar amounts of time providing care; being a carer did not relate to gender (Charles, Marshall, & Stainton, 2010). The current study contradicted previous research that concluded that there was a feminization of care in Canada (Stamatopoulos, 2015). However, the Stamatopoulos study (2015) investigated consensus data from 1996 to 2006 and used an older sample of YCs when exploring the caregiving role. With regards to the potential of having gender division of tasks, results from the present study also refuted Joseph et al. (2009) study that revealed that certain tasks (such as personal care) were gender specific (i.e., female oriented) and that as a result of caregiving, females acquired more negative consequences in comparison to males. While other studies found gender related differences (Earley et al., 2007; Warren, 2007), the present study indicated that regardless of gender, YCs were expected to help with various tasks on a daily basis. Given that many of these studies used data that were collected around the same time as the present study, there is no adequate explanation for the inconsistent gender effect findings. Many research related factors (i.e., sample size, data collection methods, criteria for identifying YCs, etc.) and extraneous variables (i.e., individual differences such as culture, age, parental influences, different countries) may contribute to these changing trends. Future studies should examine gender effects more closely and investigate whether the gender gap is, in fact, closing.

Previous literature concluded that older children usually assumed the caregiving role within the family (Banks et al., 2002; Ireland & Pakenham, 2010; Nagl-Cupal et al.,

2014; McDonald, Dew, & Cumming, 2010; Ali et al., 2012). However, in a book by Leman (1998), where birth order typical traits were discussed, caregiving would most likely be assumed by the last-born children due to their caring and lovable personalities. Moreover, it has been suggested that when siblings were present, the caregiving role was most likely to be shared among them (Lackey & Gates, 2001). The current study did not find any correlations between the caring amount and birth order or number of siblings within the family. Thus, despite prior findings, caregiving in this sample was unrelated to birth order.

To sum up, most of the findings regarding YCs from this study resembled previous research except results that demonstrated gender differences; this study did not find any differences with respect to the quantity of the provided caregiving and the types of responsibilities that males and females completed. Additionally, birth order was found to be irrelevant to caregiving. In contrast to traditional roles, caregiving was not female oriented and it was unrelated to birth order (in contrast to Stamatopoulos, 2015; Leman, 1998). Overall, YCs were shown to be a unique population of children and youth who may be a product of certain familial circumstances, and families' dependency on YCs may be minimized upon access to satisfactory support systems.

Examination of Population Differences

Only a limited number of studies have attempted to compare YCs to non-YCs, but again, no previous research has been conducted on many factors at once. When comparing YCs to non-YCs on familial structure and availability/proximity of others, only family composition was significantly different. Consistent with previous literature, the present study showed that more YCs lived in more single parent households in

comparison to non-YCs (Banks et al., 2002; McDonald, Dew, & Cumming, 2010; Ireland & Pakenham, 2010; Nagl-Cupal et al., 2014). This may suggest a need for the YC role in single parent families. However, while both YC and non-YC families had a similar number of relatives nearby, it appeared that YCs did not receive extended family support. The fact that YCs do not receive support from other family members or external services may suggest that caregiving stays within nuclear families.

Since there were no previous studies that investigated specific temperamental traits, this study was the first to explain what attributes YCs and non-YCs differed on. YCs were found to have higher activity level, higher withdrawal, lower flexibility, lower cheerfulness, less organized sleep/wake cycles, and higher distractibility. Several of these findings were illustrated in previous literature. For instance, Lloyd (2013) noted that YCs were overall less happy and had lower well-being and life satisfaction than other children at school. Moreover, although not a comparative study, Bolas, Wersch, and Flynn (2007) found that YCs were increasingly angry and frustrated. Thus, it may come as no surprise that YCs in the current study exhibited more withdrawal and less cheerful mood than the normative sample. Another study found that YCs experienced concentration difficulties (Sahoo & Suar, 2010). These results were also obtained in the current sample, as YCs demonstrated higher distractibility rates than non-YCs. Overall, temperament differences may suggest a pre-disposition to caregiving. Future studies should look at the same temperamental attributes to attempt to replicate these findings.

This study investigated qualities of attachment to mothers, fathers, and friends. In all cases, YCs showed lower qualities of attachment overall. These findings were also demonstrated in Early's et al. research (2006) that showed that caregiving hindered

relationships and increased tension between children and parents. However, the majority of studies demonstrated contrasting results; in many instances the caregiving role brought children and parents together, thereby creating feelings of closeness and trust (Earley et al., 2007; Chalmers & Lucyk, 2012; Lackey & Gates, 2001; Stallard et al., 2004; Smyth, Cass, & Hill, 2011; Doutre et al., 2013). It is important to note that none of these studies were comparative. Thus, the results could only be applicable to understanding YCs' experiences.

While it is true that lower levels of attachment could be explained by years of caregiving and one's environment at home, the current study cannot make this association as the comparison group was not measured on any of the caregiving factors. However since in this study YCs were compared to non-YCs and the only aspect that distinguishes the two groups was the caregiving factors, it could be concluded that family dynamics may be altered due to YCs' caregiving role. For instance, it may be that the lower qualities of attachment are a coping response to YCs' unpredictable environments. Maintaining distance from loved ones may serve as a protective factor in households where unpredictability and stress levels remain high. Although a comparative study by Remtulla et al. (2012) found similar levels of attachment in YCs and non-YCs, results from Shifren and Kachorek (2003) indicated that YCs' attachment with others became worse as they got older, and their relationships became less warm and supportive overall. In order to gain more consistent results, future studies should examine the attachment patterns in the two groups, have an equivalent sample size for both YCs and non-YCs, and explore the reasoning behind these trends.

With respect to the quality of attachment to friends, previous studies that specifically investigated YCs' social lives revealed that they often became isolated and restricted due to their caregiving role at home (Ali et al., 2012; Banks et al., 2002; Thomas et al., 2003; Bolas et al., 2007; Rose & Cohen, 2010). Hamilton and Adamson (2013) found that many YCs often maintained good social relationships with their friends if they were supportive of them. For others, maintaining good relationships was hard due to the lack of understanding from their friends (Moore, McArthur, & Morrow, 2009; Ali et al., 2012). Comparative studies by Collins and Bayless (2013) revealed that YCs exhibited more peer problems, while Warren (2007) showed that they were more isolated than non-YCs. Thus, it could be argued that due to the previous studies' suggestions about YCs experiencing high levels of isolation, secrecy, and peer problems, it was not surprising that YCs' attachment to their friends in the current sample was found to be lower than in non-YCs. Since none of the studies assessed peer attachment qualities directly, future studies should try to replicate these results.

The current study revealed that YCs experienced lower self-esteem than the normative population. Collins and Bayless (2013) and Banks et al. (2002) have assessed YCs' self-esteem and also found that YCs displayed lower levels than their peers. Depression was another measure that exposed population differences; YCs in the current study exhibited more depressive symptoms than non-YCs. This was consistent with other studies that indicated similar tendencies in the YC sample (Chalmers & Lucyk, 2012; Sahoo & Suar, 2010; Shifren & Kachorek, 2003). Banks' et al. research findings (2002) revealed a similar pattern when investigating YCs and non-YCs, with YCs scoring higher

on the depression scale. Taken together, lower levels of self-esteem and higher depressive symptoms could be attributed to YCs' caregiving role.

It was very surprising that YCs and non-YCs showed similar levels of loneliness, social anxiety, and bullying. A comparative study by Nagl-Cupal et al. (2014) revealed that YCs preferred to be alone more often than their peers, however the present study did not find any significant differences on the measures for loneliness. Results may be different due to the age of participants in the sample, sampling techniques, and choice of questions on the surveys. It should also be noted that while Nagl-Cupal et al. (2014) used a larger, cross-sectional sample, the age group was only 10-14 years of age. Finally, while the current study matched YCs to non-YCs, the other study identified YCs by using two criteria: the presence of an illness or a disability in the family and extent of various responsibilities at home (Nagl-Cupal et al., 2014). In contrast, the present study used a wider age group, previously identified YCs (through family members or professionals), and also may have included more reasons for caregiving such as parental absence, language barriers, and drug and/or alcohol problems.

With regards to experiences of anxiety, previous studies demonstrated that many YCs had heightened levels of anxiety due to their caregiving role at home (Ali et al., 2012; Earley et al., 2007). Sahoo & Suar (2010) revealed that YCs experienced more anxious feelings than their friends. However, there was an absence of studies that investigated social anxiety specifically. It was interesting that the present study established no differences in social anxiety levels of YCs and non-YCS. Future studies should directly investigate social anxiety in order to see if the lack of any differences is consistent in other samples.

Although bullying was not statistically and significantly different between YCs and non-YCs, there was a trend towards YCs being bullied more frequently. In previous studies, YCs experienced more bullying, teasing, and assaults from others due to their caregiving roles at home that made them somewhat different from their peers (Earley et al., 2007; Moore et al., 2009). Comparative analyses in other research studies revealed the same trend; YCs were bullied more often than other children as a result of being perceived to be different (Warren, 2007; Banks et al., 2002). Thus, it was surprising that no significant differences in bullying were found in the current study. However, the presence of the 'trend towards significance' could suggest that perhaps the current study's sample size was small in comparison to the other two studies that have successfully found significant differences between the two groups. Alternatively, bullying may not be a factor. Future studies need to examine whether or not bullying is an issue for YCs.

Finally, YCs and non-YCs displayed similar levels of life optimism. Similar results were demonstrated with other YCs who showed "fighting spirit", optimism, and inner strength despite the adversities related to their caregiving role (Doutre et al., 2013, p. 38). Thus, despite the different circumstances and potential hardships, YCs, just as non-YCs, expect the best out of life.

YC Profile and Implications

Cassidy and Giles (2013) noted that "resilience in young carers was enhanced through a positive identity as a carer based on social recognition of the value of the caring role" (p. 652). In other words, with more children being able to identify themselves as

YCs, society may finally recognize their caregiving roles and thereby contribute to greater resiliency of YCs. Thus, the main purpose of this study was to build a YC profile, by investigating individual, family and psychosocial factors at the same time, in order to enhance the identification processes.

Up until now, a YC profile has been missing in literature, thereby contributing to limited awareness and recognition of YCs altogether. However, the importance of identification has been discussed in previous studies, especially noting how several professionals should play a role in this process. For instance, Nagl-Cupal et al. (2014) and Warren (2007) urged teachers, hospital staff, and other health professional to promote early identification of YCs. Smyth et al. (2011) advised for better referral services. Thus, it could be argued that the best way to enhance the identification process is through the creation of a YC profile which would also be beneficial to YCs themselves.

Although the formation of a profile is only in its initial stages, this study found many similarities and differences between the two matched groups which yielded benefits to theory, practice, and future research directions. Theoretically, this study promoted a greater understanding of the factors that differentiated YC from non-YC populations, giving rise to YCs' unique characteristics. Practically, by building a profile, this study hoped to increase knowledge in the professional field and improve the identification process which could lead to greater societal recognition of the YC population and to improved outcomes for YCs themselves. Professionals and program delivery staff may also use this profile to note potential risk or protective factors that correspond to YCs' caregiving role. Moreover, this profile could influence future policy by providing funding for interventions that would enhance support plans to make YCs' lives as normal and

rewarding as possible. For example, Harstone, Bergen, and Sweetgrass (2010) noted that new policies should aim to enhance service provision and reduce familial reliance on YCs from the start. Finally, future studies may use this profile to see if the similarities and differences remain consistent in other samples. Replication is key to increasing awareness, understanding, and support for YCs.

Limitations and Future Research Directions

Although there was a large sample size overall (N = 248), this study included only 124 YCs. This limited quantity may be a function of this population's hidden and sensitive nature. As previously mentioned, some families may purposefully try to maintain secrecy, and therefore there would be an inherent difficulty in trying to gain a larger number of signed consent forms. Due to the nature of this population, it was unreasonable to obtain participation by random sampling methods. Instead, this study relied on a targeted sample of YCs who were already a part of an organization. This is also a limitation, as only identified YCs were used in this study. Thus, the results may not be generalizable to other YC populations.

Moreover, since the YCs in this sample were involved with an organization, they were potentially subjected to certain benefits and supports. Thus, it could be that this sample of children and youth represented YCs who have minimal caregiving responsibilities. Other YCs, who may possess heavier caregiving duties and are farther on the continuum of care, were not a part of the present study. Again, this may yield some generalization difficulties.

Additionally, this study included self-administered, lengthy questionnaires. It is a limitation because there was a potential for errors and incomplete responses. To

overcome this, the current data were carefully scanned for outliers and missing values; the two data sets were cleaned prior to analyses. The length of the questionnaires had the potential to impact survey completion. Since the deletion of some participants was not possible (in order to maintain sample size), missing data were imputed. All subsequent analyses were reviewed by looking at the first imputed data set and comparing it to the original version.

Although this study investigated population differences, it was impossible to compare YCs' responsibilities to their friends because the non-YC sample did not contain the same questions. Instead, this study relied on YCs' perceptions of how their caregiving responsibilities were different from their peers. Correspondingly, this could be a limitation because YCs may not want to feel different from others, especially if it could potentially increase victimization. Thus, it could be that even though they felt as though their responsibilities exceeded their friends', they kept it hidden from others. Another possible limitation was that even though this study aimed to examine YCs' responsibilities, some of them may not be aware that what they do is a "responsibility"; instead, as mentioned earlier, some may perceive their tasks as normal activities they (as sons or daughters, brothers or sisters) do for their family. This could explain why certain answers may have been left unanswered.

Another potential limitation was the use of education as a proxy for Social and Economic Status (SES). There have been studies that suggested that using a sole indicator for SES may lead to misleading results (Braveman et al., 2005). Moreover, using a single proxy, such as education, as basis for matching criteria has been greatly discouraged (Liberatos, Link, & Kelsey, 1988). However, given that most children are unaware of

their parents' income level, using a proxy may yield better results. For instance, using education as a proxy has been very popular in research since higher education is believed to coincide with higher income and better occupation (Lien, Friestad, & Klepp, 2001). Thus, although this study used education as a proxy for SES, it was only required for demographic purposes and not as a part of the matching criteria.

Moreover, the two questionnaires that yielded two different samples were not administered during the same year. The YLC-CURA surveys were completed in 2001, while the Hear Me Now surveys were collected since 2006. Regardless of the year differences, this study matched the two samples on age, gender, and number of siblings within the family. Moreover, a random subset of a sample (n = 991) was taken from the large YLC-CURA data base. Thus, this study did not expect cohort effects.

Finally, this study was exploratory and suggestive in nature. Thus, all findings regarding YCs' roles within the family and their differences to non-YCs must be replicated to confirm results. While there is an abundance of research regarding what YCs do and how it affects them, future studies should question what factors may be responsible for YCs' differential outcomes from non-YCs. Variables such as temperament and birth order are still missing in the literature. Thus, in order to replicate these findings, future studies should investigate temperamental attributes, birth order, gender, and other features, and understand which factors may elicit the caregiving role within the family.

Notwithstanding the limitations, the present study increased awareness of unique aspects of YCs not only within the family context, but also through a population comparison in a Canadian context, which allowed for the development of a YC profile.

Conclusion

YCs represent a hidden population of children and youth who provide care for their family members despite the hardships they may endure in their daily lives. The lack of awareness and knowledge of YCs makes them an increasingly vulnerable population. Since there was no method for identifying who is a YC within the family, the first step was to learn more about who they were and whether they differed from their peers. By simultaneously combining family, individual, and psychosocial factors, the remarkable and unprecedented results yielded a YC profile.

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Appendix A: Demographics (both Hear Me Now and YLC-CURA)

Age:

1. How old are you?

○ 8 ○9 ○10 ○11 ○12 ○ 13 ○ 14 ○ 15 ○ 16 ○ 17 ○ 18 or over

Gender:

2. Are you male or female?

○ Male ○ Female

Grade:

3. What grade are you in?

○ 3rd grade ○ 4th grade ○ 5th grade ○ 6th grade ○ 7th grade ○ 8th grade

○ 9th grade ○10th grade ○ 11th grade ○ 12th grade

Place of Birth:

4. Were you born in Canada?

○ Yes ○ No ➔ If No, how long have you been living in Canada? _____

Ethnicity:

5. Other than Canadian, is there another culture or ethnic background that your family belongs to?

○ Yes ○ No
⬇
If yes, which one? *(Fill in all that apply)*

○ American ○ French ○ Italian ○ Russian ○ East Indian ○ Chinese
○ German ○ Korean ○ Ukrainian ○ West Indian ○ Dutch ○ Greek
○ Native/Aboriginal ○ African ○ Latin American ○ British ○ Hungarian
○ Polish ○ Other - Which one? _____

Appendix B: Caregiving (Hear Me Now ONLY)

Who needs care:

1. Which of your relatives needs care/assistance?

○Mother	○Brother	○Grandfather
○Father	○Uncle	○Grandmother
○Sister	○Aunt	○Other_____

Why care required:

2. Why does your relative need care/assistance? E.g., Alzheimer's, MS, depression, substance abuse, Down's, autism, language, etc.

_____

Length of time (years) and starting point:

3. For approximately how many years has your relative needed care/assistance? _____

4. Approximately how old were you when your relative began to need care/assistance?__

Amount of time spent caring:

5. On average, approximately how much time do you spend caring/helping others in the home each day?

○ Less than 1 hour	○ 3-4 hours	○ 7-8 hours
○1-2 hours	○ 5-6 hours	○ 9 hours or more

Caregiving responsibilities and comparison to friends' responsibilities:

6. At home, are you expected to help with:

	Rarely	Occasionally	Some times	Usually	Most Of the time	Does not apply
Household tasks (e.g., laundry, house cleaning, gardening)	….○...	……○…	….○..	….○….	….○….	…○...
Meal preparation	….○..	……○…	….○..	….○….	….○….	…○…
Babysitting for brothers and sisters	….○..	……○…	….○..	….○….	….○….	…○…
Personal care for the relative who need scare (e.g., help with bathing, toileting, etc.)	….○..	……○…	….○..	….○….	….○….	…○..
Providing medical care for the relative who needs care (e.g., giving pills, giving needles, attending appointments)	….○..	……○…	...○….	….○….	….○….	…○…
Managing the house (e.g., paying bills)	….○..	……○…	….○..	….○….	….○….	…○…
Translation	….○	……○…	….○...	….○…	….○….	…○…

7. Compared to your friends, how would you describe your responsibilities for:

	Much lower	Lower	About the same	Higher	Much higher	Does not apply
Household tasks (e.g., laundry, house cleaning, gardening, etc.)	..○..	..○..	..○..	..○..	..○..	..○..
Meal preparation	..○..	..○..	..○..	..○..	..○..	..○..
Personal care for the relative who needs care (e.g., help with bathing)	..○..	..○..	..○..	..○..	..○..	..○..
Babysitting for brothers and sisters	..○..	..○..	..○..	..○..	..○..	..○..
Providing medical care for the relative who needs care	..○..	..○..	..○..	..○..	..○..	..○..
Managing the house (e.g., paying bills)	..○..	..○..	..○..	..○..	..○..	..○..
Translation	..○..	..○..	..○..	..○..	..○..	..○..
Taking care of yourself (e.g., making own lunches, doing homework)	..○..	..○..	..○..	..○..	..○..	..○..

Services received:

8. What types of support does your family currently receive? This includes support for yourself, the person who needs care, and the rest of the family. Please check all that apply.

○ None	○ Nursing services	○ Homecare	○ Educational support
○ Support groups	○ Agencies (e.g., MS or Alzheimer's Society)	○ Counselling	○ Other_____

Appendix C: Parental SES (both Hear Me Now and YLC-CURA)

Mothers' SES:

The following questions are about your mother/stepmother (female guardian) whom you live with the MOST.

What is the highest level of education your mother/stepmother (female guardian) completed?

- ○ Did not finish high school
- ○ Finished high school
- ○ Some college, university, or apprenticeship program
- ○ Completed a college/apprenticeship diploma (e.g., electrician) and/or technical diploma (i.e. Graphic design, hair dressing)
- ○ Completed a university undergraduate degree
- ○ Completed a professional degree (e.g., masters, PhD, medical doctor, lawyer)
- ○ Still going to school
- ○ Don't know

Fathers' SES:

The following questions are about your father/stepfather (male guardian) whom you live with the MOST.

What is the highest level of education your FATHER/STEPFATHER (male guardian) completed?

- ○ Did not finish high school
- ○ Finished high school
- ○ Some college, university, or apprenticeship program
- ○ Completed a college/apprenticeship diploma (e.g., electrician) and/or technical diploma (i.e. Graphic design, hair dressing)
- ○ Completed a university undergraduate degree
- ○ Completed a professional degree (e.g., masters, PhD, medical doctor, lawyer)
- ○ Still going to school
- ○ Don't know

Appendix D: Family Information/ Structure (both Hear Me Now and YLC-CURA)

Family composition:

1. Whom do you live with right now? *(Fill in all that apply)*

○ Both birth parents
○ Birth father only
○ Birth mother only
○ Birth mother and stepfather
○ Birth father and stepmother
○ Neither birth parent
○ Adoptive parents
○ Foster parents
○ Legal guardian
○ Grandparent(s)
○ Other relatives
○ On your own
○ With roommates
○ Group home
○ Other: _____

Birth order:

2. How many brothers or sisters do you have?

○ NONE ○ ONE ○ TWO ○ THREE ○ FOUR OR MORE

3. How many YOUNGER brothers or sisters do you have?

○ NONE ○ ONE ○ TWO ○ THREE ○ FOUR OR MORE

4. How many OLDER brothers or sisters do you have?

○ NONE ○ ONE ○ TWO ○ THREE ○ FOUR OR MORE

Availability and proximity of others:

5. How many OTHER people live in your home?

○ 1 ○ 2 ○ 3-4 ○ 5-6 ○ 7 or more

6. Do you have other family members who live close by?

○ Yes ○ No

Appendix E: Parental attachment (both Hear Me Now and YLC-CURA)

Attachment to mother:

Think about your mother/stepmother (female guardian) whom you live with the MOST and answer these questions.

	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
My mother trusts my judgement	...○...	...○...	...○...	...○...
My mother accepts me as I am	...○...	...○...	...○...	...○...
I like to get my mother's point of view on things I'm concerned about	...○...	...○...	...○...	...○...
My mother can tell when I'm upset about something	...○...	...○...	...○...	...○...
Talking over my problems with my mother makes me feel ashamed or foolish	...○...	...○...	...○...	...○...
My mother expects too much from me	...○...	...○...	...○...	...○...
I get upset a lot more than my mother knows about	...○...	...○...	...○...	...○...
When we discuss things, my mother cares about my point of view	...○...	...○...	...○...	...○...
My mother has her own problems, so I don't bother her with mine	...○...	...○...	...○...	...○...
I tell my mother about my problems and troubles	...○...	...○...	...○...	...○...
I feel angry with my mother	...○...	...○...	...○...	...○...
My mother understands me	...○...	...○...	...○...	...○...
I trust my mother	...○...	...○...	...○...	...○...
My mother doesn't understand what I'm going through these days	...○...	...○...	...○...	...○...
I get upset easily around my mother	...○...	...○...	...○...	...○...
I don't get much attention from my mother	...○...	...○...	...○...	...○...
I can count on my mother when I need to get something off my chest	...○...	...○...	...○...	...○...

Attachment to father:

Think about your father/stepfather (male guardian) whom you live with the MOST and answer these questions.

	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
My father trusts my judgement	...…○...	...…○...	….…○…...	…○...
My father accepts me as I am	...…○...	...…○...	….…○…...	…○...
I like to get my father's point of view on things I'm concerned about	...…○...	...…○...	….…○…...	…○...
My father can tell when I'm upset about something	...…○...	...…○...	….…○…...	…○...
Talking over my problems with my father makes me feel ashamed or foolish	...…○...	...…○...	….…○…...	…○...
My father expects too much from me	...…○...	...…○...	….…○…...	…○...
I get upset a lot more than my father knows about	...…○...	...…○...	….…○…...	…○...
When we discuss things, my father cares about my point of view	...…○...	...…○...	….…○…...	…○...
My father has his own problems, so I don't bother him with mine	...…○...	...…○...	….…○…...	…○...
I tell my father about my problems and troubles	...…○...	...…○...	….…○……	…○...
I feel angry with my father	...…○...	...…○...	...…...○…...	…○...
My father understands me	...…○...	...…○...	….…○…...	…○...
I trust my father	...…○...	...…○...	….…○…...	…○...
My father doesn't understand what I'm going through these days	...…○...	...…○...	….…○…...	…○...
I get upset easily around my father	...…○...	...…○...	….…○…...	…○...
I don't get much attention from my father	...…○...	...…○...	….…○…...	…○...
I can count on my father when I need to get something off my chest	...…○...	...…○...	….…○…...	…○...

Appendix F: Attachment to Friends (both Hear Me Now and YLC-CURA)

Think about your FRIENDS and answer the following questions:

	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
I like to get my friends' points of view on things I'm concerned about	….O…	….O…	……O……..	…..O…..
My friends can tell when I'm upset about something	…..O…	…O…	……O..….	…..O…..
When we discuss things, my friends care about my point of view	……O…	…O…	……O..….	…..O…..
Talking over my problems with my friends makes me feel ashamed and foolish.	……O…	…O…	……O..….	…..O…..
I wish I had different friends	……O…	…O…	……O……..	…..O…..
My friends understand me	……O…	…O…	……O……..	…..O…..
My friends accept me as I am	……O…	…O…	……O..….	…..O…..
My friends don't understand what I'm going through these days	……O…	…O…	……O..….	…..O…..
I feel alone or apart when I am with my friends	……O…	…O…	……O..….	…..O…..
My friends listen to what I have to say	……O…	…O…	……O..….	…..O…..
My friends are fairly easy to talk to	……O…	…O…	……O..….	…..O…..
My friends are concerned about my well being	……O…	…O…	……O..….	…..O…..
I feel angry with my friends	……O…	…O…	……O……..	…..O…..
I can count on my friends when I need to get something off my chest	……O…	…O…	……O..….	…..O…..
I trust my friends	……O…	…O…	……O..….	…..O…..
I get upset a lot more than my friends know about	……O…	…O…	……O……..	…..O…..
It seems as if my friends are irritated with me for no reason	……O…	…O…	……O..….	…..O…..
I tell my friends about my problems and troubles	……O…	…O…	……O..….	…..O…..

Appendix G: Temperament (both Hear Me Now and YLC-CURA)

Fill in the circle that best described you:	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
I laugh and smile at a lot of things	…○…	…..○…	…. ○…	….○…
It takes me a long time to get used to new things at home	…○…	…..○…	…. ○…	….○…
I wake up at different times	…○…	…..○…	…. ○…	….○…
Once I am doing something, nothing can distract me from it	…○…	…..○…	… .○…	….○…
When I do things, I do them until they are finished	…○…	…..○…	…..○…	….○…
I have a hard time sitting still	…○…	…..○…	…..○…	….○…
I can make myself at home anywhere	…○…	…..○…	…..○…	….○…
I can be distracted by something else, no matter what I might be doing	…○…	…..○…	…..○…	….○…
I stay with an activity for a long time	…○…	…..○…	…..○…	….○…
If I have to stay in one place for a long time, I get very restless	…○…	…..○…	…..○…	….○…
I am interested in new objects shown to me	…○…	…..○…	…..○…	….○…
I like trying new things	…○…	…..○…	…..○…	….○…
It takes me a long time to adjust to new schedules	…○…	…..○…	…..○…	….○…
If something can go wrong for me, it will	….○…	..…○…	…..○…	….○…
I feel good about my future	….○…	..…○…	…..○…	….○…
I don’t expect things to go my way	….○…	..…○…	…..○…	….○…
No matter when I go to sleep, I wake up at the same time the next morning	….○…	…..○…	...○….	..○…
My mood is generally cheerful	….○…	…..○…	...○…..	..○…
I do not like changes in routine	….○…	…..○…	...○…..	..○…
I laugh several times a day	….○…	…..○…	...○…..	..○…
My first response to anything new is to be interested in it	….○…	…..○…	...○…..	..○…
If I am doing one thing, something else happening won’t get me to stop	….○…	…..○…	...○…..	..○…
Once I start something, I finish it	….○…	…..○…	...○…..	..○…
Even when I am supposed to be still, I get fidgety after a few minutes	….○…	…..○…	...○…..	..○…
I get the same amount of sleep each night	….○…	…..○…	...○…..	..○…
I like meeting new people	….○….	…..○…	...○….	..○…
I smile often	….○….	…..○…	...○….	..○…
I have trouble getting to sleep at night	….○….	…..○…	...○….	..○…
Changes in plans make me restless	….○…	…..○…	...○….	..○…
I am happy with my life	….○..	…..○…	...○….	..○…
I expect the best	….○….	..…○...	..○….	..○…

Appendix H: Depression (both Hear Me Now and YLC-CURA)

Fill in the answer that best describes how often you felt or behaved this way DURING THE PAST TWO WEEKS.

	NONE OF THE TIME (LESS THAN 1 DAY)	RARELY (1-2 DAYS)	SOME OF THE TIME (3-5 DAYS)	OCCASIONALLY (6-9 DAYS)	MOST OF THE TIME (10-14 DAYS)
I was happy	.....O.....	.....O....	.....O.....	.....O....	.....O....
I did not feel like eating; my appetite was poor	.....O.....	.....O....	.....O.....	.....O....	.....O....
I felt that I could not stop feeling sad, even with help from my family and friends	.....O.....	.....O...	.....O.....	.....O....	.....O....
I felt that I was just as good as other people.	.....O.....	.....O...	.....O....	.....O....	.....O....
I had trouble keeping my mind on what I was doing	.....O.....	.....O...	.....O.....	.....O....	.....O....
I felt depressed	.....O.....	.....O...	.....O.....	.....O....	.....O....
I felt that everything I did was an extra effort	.....O.....	.....O...	.....O.....	.....O....	.....O....
I felt hopeful about the future	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I thought my life had been a failure	.....O.....	.....O...	.....O.....	.....O.....	.....O.....
I felt fearful	.....O.....	.....O...	.....O.....	.....O.....	.....O.....
My sleep was restless	.....O.....	.....O...	.....O.....	.....O.....	.....O.....
I was bothered by things that usually don't bother me	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I talked less than usual	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I felt lonely	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
People were unfriendly	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I felt like doing nothing	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I had crying spells	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I felt sad	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I felt that people disliked me	.....O.....	.....O..	.....O.....	.....O.....	.....O.....
I enjoyed life	.....O.....	.....O..	.....O.....	.....O.....	.....O.....

Appendix I: Self-Esteem (both Hear Me Now and YLC-CURA)

Fill in the answer that best describes the way you feel:

	STRONGLY AGREE	AGREE	NEITHER AGREE NOR DISAGREE	DISAGREE	STRONGLY DISAGREE
On the whole I am satisfied with my life	….O….	…O…	…O…	…O…	…..O…..
I feel that I have a number of good qualities	….O….	…O….	…O…	…O…	…..O…..
I am able to do things as well as most people	….O….	…O….	…O…	…O…	…..O…..
I feel I do not have much to be proud of	….O….	…O….	…O…	…O...	…..O…..
I feel useless at times	….O….	…O….	…O…	…O…	…..O…..
I feel that I am a person of worth, at least equal with others	….O….	…O….	…O…	…O…	…..O…..
I wish I could like myself more	….O….	…O….	…O…	…O…	…..O…..
All in all, I tend to feel that I am a failure	….O….	…O….	…O…	…O…	…..O…..
At times I think I am no good at all	….O….	…O…	…O…	…O…	…..O…..
I take a positive attitude toward myself	….O….	…O….	…O…	…O…	…..O…..

Appendix J: Social Anxiety (both Hear Me Now and YLC-CURA)

In the chart below, fill in the answer that best suits you:

	ALMOST NEVER OR NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS OR ALWAYS
I'm quiet when I'm with a group of other people my age	…..○…..	…….○…...	…..○…..	…….○…
I only talk to other people my age that I know really well	…..○…..	…….○…...	…..○…..	…….○…
I feel that other people my age talk about me behind my back	…..○…..	…….○…...	…..○…..	…….○…
I worry about what other people my age think of me	…..○…..	…….○…...	…..○…..	…….○…
I feel that other people my age are making fun of me	…..○…..	…….○…...	…..○…..	…….○…
I'm afraid that other people my age will not like me	…..○…..	…….○…...	…..○…..	…….○…
If I get into an argument with another person, I worry that he or she won't like me.	…..○…..	…….○…...	…..○…..	…….○…
I worry about being teased.	…..○…..	…….○…...	…..○…..	…….○…
I feel shy with people my age that I don't know	…..○…..	…….○…...	…..○…..	…….○…
I get nervous when I talk to people my age that I don't know very well	…..○…..	…….○…...	…..○…..	…….○…
I worry about doing something new in front of other people my age	…..○…..	…….○…...	…..○…..	…….○…
I feel shy even with other people my age I know well	…..○…..	…….○…...	…..○…..	…….○…
It's hard for me to ask other people my age to hang out with me	…..○…..	…….○…...	…..○…..	…….○…
I'm afraid to invite other people my age to my house because they might say no	…..○…..	…….○…...	…..○…..	…….○…

Appendix K: Loneliness (both Hear Me Now and YLC-CURA)

Aversion to loneliness:

	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
If I am lonely I go to see other people	…O…	……O…	……O….	…..O…..
I am unhappy when I have to do things on my own	…O…	……O…	……O….	…..O…..
If I am alone, I feel unhappy	….O…	……O…	……O….	…..O…..
If I am bored, I feel lonesome	…O…	……O…	……O….	…..O…..
If I feel bored, I am unhappy	…O…	……O…	……O….	…..O…..
To really have a good time I have to be with my friends	…O…	……O…	……O….	…..O…..
If I am alone, I would like to have other people around	…O…	……O…	……O….	…..O…..
If I am lonely, I don't know what to do	…O…	……O…	……O….	…..O…..

Affinity for loneliness:

	ALMOST ALWAYS OR ALWAYS	OFTEN	SOMETIMES	ALMOST NEVER OR NEVER
To think something over, I want to be alone	……O…	……O…	……O…	…..O…..
If I have an argument with someone, I want to be alone to think it over	……O…	……O…	……O…	…..O…..
I am happy if I am the only one at home, because I can do some quiet thinking then	…….O…	……O…	……O…	…..O…..
I want to be alone	……O…	……O…	……O…	…..O…..
I get away from others because they disturb me with their noise	……O…	……O…	……O…	…..O…..
Being alone helps me renew my courage	……O…	……O…	……O…	…..O…..
I like to do things on my own at home	……O…	……O…	……O…	…..O…..
When I am alone, I quiet down	……O…	……O…	……O…	…..O…..

Appendix L: Bullying (both Hear Me Now and YLC-CURA)

How often have these things been <u>DONE TO YOU</u> during the LAST SCHOOL YEAR?

	NEVER	A FEW TIMES A YEAR	A FEW TIMES A MONTH	A FEW TIMES A WEEK	EVERY DAY
Been pushed and shoved	...○...	.....○...	....○...	....○..	.....○..
Been sworn at and called names	...○...	.....○...	....○...	....○..	.....○..
Received hurtful and unsigned notes	...○...	.....○...	....○...	....○..	.....○..
Been excluded from joining an activity	...○...	.....○...	....○...	....○..	.....○..
Had things taken away from you	...○...	.....○...	....○....	....○..	.....○..
Been teased and ridiculed	...○...	.....○...	....○....	....○..	.....○..
Been threatened and intimidated	...○...	.....○...	....○....	....○..	.....○..
Had rumours and untrue stories of you spread around	...○...	.....○...	....○....	....○..	.....○..
Been kicked and hit	...○...	.....○...	....○....	....○..	.....○..
Had another student dare someone to hurt you	...○...	.....○...	....○....	....○..	.....○..
Had a gang of students pick a fight with you	...○...	.....○...	....○....	....○..	.....○..
Had a group of students picking on you	...○...	.....○...	....○....	....○..	.....○..

How often have <u>YOU DONE</u> these things during the LAST SCHOOL YEAR?

	NEVER	A FEW TIMES A YEAR	A FEW TIMES A MONTH	A FEW TIMES A WEEK	EVERY DAY
Pushed and shoved someone	...O...	.....O...	.....O...	...O...	.....O...
Swore at someone and called them names	...O...	.....O...	.....O...	...O...	.....O...
Wrote hurtful and unsigned notes	...O...	.....O...	.....O...	...O...	.....O...
Excluded someone from joining an activity	...O...	.....O...	.....O...	...O...	.....O...
Demanded and took things from others	...O...	.....O...	.....O...	...O...	.....O...
Teased and ridiculed someone	...O...	.....O...	.....O...	...O...	.....O...
Threatened and intimidated someone	...O...	.....O...	.....O...	...O...	.....O...
Spread rumours and untrue stories	...O...	.....O...	.....O...	...O...	.....O...
Kicked and hit someone	...O...	.....O...	.....O...	...O...	.....O...
Dared another student to hurt someone	...O...	.....O...	.....O...	...O...	.....O...
Been part of a gang of students picking fights	...O...	.....O...	.....O...	...O...	.....O...
Been part of a group of students picking on someone	...O...	.....O...	.....O...	...O...	.....O...

Appendix M: Survey scales: Not included or reverse coded items (both Hear Me Now and YLC-CURA)

	Temperament		Loneliness	Self-Esteem	Attachment		Depression	
Surveys	Items not included	Items reversed	Items not included	Items reversed	Items not included	Items reversed	Items not included	Items reversed
Hear Me Now (Younger version)	-	**PT1**: 2, 3, 8, 14, 15 **PT2**: 3	-	3, 4, 6, 7, 8	-	**MQ**: 6, 9 **DQ**: 6, 9 **FQ**: 5	-	4, 8, 12, 16
Hear Me Now (Older version)	-	**PT1**: 2, 3, 8, 14; **PT2**: 15, 3	-	3, 4, 6, 7, 8	**PT2**: 8	**MQ**: 6, 9 **DQ**: 6, 9 **FQ**: 5	-	4, 8, 12, 16
YLC-CURA Elementary	**PT1**: 3-5, 7-11 **PT2**: 2-6, 8-9, 11-13	**PT1**: 2, 14, 15	1, 4, 5, 3, 4, 8.	3, 4, 6, 7, 8	**PT1**: 1, 3, 17 **PT2**: 1, 3, 17	**MQ**: 6, 9 **DQ**: 6, 9 **FQ**: 5	1-20	-
YLC-CURA Secondary school	**PT1**: 13 **PT2**: 13	**PT1**: 2, 3, 8, 14, 15; **PT2**: 3	-	3, 4, 6, 7, 8	-	**MQ**: 6, 9 **DQ**: 6, 9 **FQ**: 5	-	4, 8, 12, 16

Note: The numbers represent items on the scale. PT1 = part one; first section of the scale. PT2 = part two; second section of the scale. Attachment: MQ = mother quality, DQ = dad quality, FQ = friendship quality. Composite variables that were not listed above (i.e. bullying, anxiety) included all variables in the analyses and were not reversely coded. Any items that were not included in the analyses were deemed as 'appropriately missing' and thus were not imputed.

Appendix N: Parental Consent Form

- I understand that this study will involve answering a series of questions concerning their life and experiences.
- I understand that this study will help gain a better understanding of the experiences of a young carer, and as such, will be of benefit to my child by developing more effect ways to support them at the Powerhouse Project.
- I understand that my child will be asked to answer a number of questions about their lifestyle choices and experiences (e.g., questions about caring responsibilities, health, daily hassles, goals, anxiety, friendship quality, etc.).
- I understand that my child's participation in this study is voluntary and that my child may withdraw from the study at any time up to the submission of their survey and for any reason without penalty. I understand that the survey will approximately take 1 hour to complete.
- I understand that there is no obligation for my child to answer any question in the survey that they do not wish to answer.
- I understand that I have been informed about the study and have consented to my child's participation, although this does not mean that she/he must participate.
- I understand that all data will be kept confidential and only the researchers will have access to the data.
- I understand that my child's anonymous and confidential data may be included in a database to be used by other students at Brock University for theses and projects.
- I understand that there are very minimal potential risks to my child's participation in this study. Based on previous experience, we do not anticipate that your child will experience any negative feelings about the survey. In the rare case that your child becomes upset, they will be provided with phone numbers of support agencies in your area and staff are available to speak with them.
- I understand that only group data will be reported and no information about individual responses will ever be given to agencies, agency staff, or anyone else, including myself.
- I understand that the anonymous data will be retained indefinitely and will be securely stored in a locked office in the research laboratory at Brock University. Group data only may be published, presented at conferences, used to evaluate programs, or used in other studies. A copy of the report will be available at the Powerhouse Project in summer 2013.
- I understand that my family will be entered into a draw for a $100 gift certificate to Walmart. The draw will take place at the completion of data collection, approximately April 2013. I understand that my child will receive pizza and pop while completing the survey. I understand that my child and my family are entitled to receive these benefits even if my child withdraws from the anonymous study. My child can withdraw up to the time they hand in the survey. If they withdraw, their survey will be torn up and confidentially shredded.

This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [#12-140]. If you have any questions about your rights as a

participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

If you have any questions or concerns about your participation in this study, please contact:

Samantha Brandow Student Researcher Brock University sb09vo@brocku.ca 425	Dr. Heather Chalmers Associate Professor Director Brock University 905-688-5550, ext. 3191 hchalmers@brocku.ca mlewis@powerhouseproject.ca	Michelle Lewis Interim Executive Powerhouse Project 905-397-4201, ext.

Name of Child #1 (Please Print) _____

Name of Child #2 (Please Print) _____

Name of Child #3 (Please Print) _____

Name of Child #4 (Please Print) _____

Name of Parent/Guardian (Please Print) _____

Parent/Guardian Signature _____

Date_____

Appendix O: Participant's Assent Form

- You are invited to participate in a study that will involve answering questions about your life that will be used in research.
- You will be asked to do a survey that includes questions about your life and experiences. The survey will take about 60 minutes.
- By participating in the study you will provide valuable information that will help other children in a caregiving role. You will get pizza and pop for participating and your parents will be entered into a draw for a Walmart gift certificate.
- There is a small chance that you may become upset by this survey. However, other kids have completed this survey before and were not upset, so we do not expect you will experience any bad feelings. If you do have questions or concerns, the researchers or Powerhouse staff will be able to answer your questions and other contacts in my area will be provided to me.
- We will not tell anyone the answers that you provide. Meaning your parents, friends or the Powerhouse staff will not know your answers. Your name will not be included in the report.
- Your responses will be kept in a locked office at Brock University and only the researchers will be able to see your data.
- The surveys will be destroyed after 8 years but the information will be kept in a safe database forever. Other students at Brock University may look at the database to do assignments at school.
- Although your parents know about the study and have given permission for you to participate, you may choose not to take part. You can choose not to answer any of the questions. You can stop participating in the study at any time while doing the survey. You will still get the pizza, pop and be entered into the draw.
- If you decided you don't want your answers to be used once you have started the survey, your survey will be ripped up and destroyed. After you hand in your survey, your answers cannot be removed from the study.
- Study results may be put into journals or made into presentations. We will provide a copy of the results to the Powerhouse Project so you may see it.
- If you have any questions you can talk to Dr. Heather Chalmers at 905-688-5550 ext. 3191(or by email at hchalmers@brocku.ca) or Samantha Brandow at sb09vo@brocku.ca.
- This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [12-140]. If you have any questions about your rights as a participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

I agree to participate in this study described above. I have chosen this based on the information I have read in the Information/Consent Letter. I have had the chance to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____Signature:_____ Date:_____

Thank you for your help in this project. Please keep a copy of this form for your records.